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ABSTRACT

This training manual provides vocational rehabilitation and school counselors with background information and practical tools related to fetal alcohol syndrome (FAS), with particular reference to the needs of Native Americans. The most recent reliable data (1990) for American Indians and Alaska Natives show a rate of FAS over 10 times the national rate. People with FAS or fetal alcohol related conditions (FARC) are at high risk for learning disabilities, hearing impairments, and mental retardation. Section 1 of the manual presents current definitions of FAS and FARC, summarizes the diagnostic process, and outlines embryological origins. Section 2 explores common primary and secondary disabilities associated with FAS and FARC, as well as their impact on long-term functioning and vocational placements. Section 3 looks at common tools in the functional assessment of people with FAS or FARC, including one for use by vocational high school counselors. Section 4 is a practical guide to developing an individualized plan for employment, education, services, or programs. Trainees are asked to develop a plan for each of three illustrative case studies. Sections 5 and 6 cover the design, implementation, and ongoing evaluation and adjustment of an individualized plan and provide additional practice for the trainee. Appendices include the Fetal Alcohol Exposure Risk Assessment for Adolescents and Adults; an outline of psychosocial needs associated with FAS in adolescents and adults; "Vocational Development for Individuals with Fetal

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Alcohol Syndrome or Fetal Alcohol Effects" (Georgiana Wilton); and
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Fetal Alcohol Syndrome:
A Training Manual to Aid in Vocational Rehabilitation and Other Non-medical Services

August, 1999

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FOREWORD

This training manual is a compilation of many years of study, research, and experience in the fields of fetal alcohol syndrome (FAS) and vocational rehabilitation (VR). FAS is both a complicated condition and a simple one if the reader will remember that the primary condition associated with FAS is permanent brain damage. Due to the complexities of this field, however, the training of others in FAS is not a task to be taken lightly. This manual does not fully include the guidance and feedback given by professional trainers. Therefore, this manual should only be used in an appropriate fashion and by properly trained professionals.

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Fetal Alcohol Syndrome:
A Training Manual to Aid in Vocational Rehabilitation
and Other Non-medical Services

"Let us put our heads together and see what kind of life we can make for our children."

–Sitting Bull

Self-determination has been a phrase to live by in Native communities since the Indian Self-Determination Act was passed in 1975. It is a marvelous concept and one to be embraced. But . . . What if you are a child, adolescent, or adult with prenatal exposure to alcohol? Self-determination can, if preventive steps are not taken, turn into self-termination. The purpose of this training manual is to provide vocational rehabilitation (VR) and school counselors with background information and tools as an adjunct to training. With this information, trainees will be better equipped to help people with fetal alcohol syndrome (FAS) and related conditions to fulfill educational or employment goals and to reach their full potential.

Since FAS was first defined as a medical syndrome in 1973, the extent of knowledge in the field has expanded dramatically. The highest incidence rates yet reported are associated with certain American Indian reservations and Canadian reserves, although the incidence rates in other American Indian communities are less than the national average (Stratton, Howe, & Battaglia, 1996, pp. 83–89). The most recent *reliable* data (for the year 1990) for American Indians and Alaska Natives show a rate of FAS more than 10 times the rate for the total population. More recent data (for the year 1993), while considered less reliable (National Center for Health Statistics, 1997, p. 130), indicate even higher rates for American Indians and Alaska Natives (Boufford, 1997). As American Indian and Alaska Native adults who can compete in the modern labor

market leave their communities for higher paying jobs elsewhere, the number of adults who have fetal alcohol syndrome (FAS) or fetal alcohol related conditions (FARC) in these communities may become more inflated, and may become a more noticeable and significant problem requiring attention. People who are diagnosed with FAS/FARC are at high risk for learning disabilities, hearing impairments, and mental retardation.

This manual is intended to aid the trainee in the following areas:

- Understanding what fetal alcohol syndrome is and what it is not (Section I). This section of the manual presents the current definitions of FAS and FARC. Included in this section are a summary of the diagnostic process and an outline of the embryological origins of FAS.
- Recognizing and assessing primary and secondary disabilities associated with FAS/FARC (Section II). This section explores the common primary and secondary disabilities or conditions associated with FAS and FARC as well as their impact on long-term functioning and vocational placements.
- Screening for FAS or FARC (Section III). The third section explores the common tools used in the functional assessment of people with FAS and FARC. One of the items, the Fetal Alcohol Exposure Risk Assessment For Adolescents And Adults, is intended to help the vocational high school counselor screen for FAS/FARC and, if appropriate refer for a diagnostic evaluation or further testing.
- Developing an individualized plan for employment, education, services, or programs (Section IV). The fourth section is a practical guide for using the material gained through assessment and screening of the client to write a viable, appropriate, and practical IxP [(Individualized Education Plan (IEP), Individualized Service Plan (ISP), or Individualized Plan for Employment (IPE)]. Three case studies are provided to help illustrate the points outlined above. Trainees are asked to use the knowledge gained to outline an appropriate plan for each of these case studies.
- Designing and aiding the implementation of an individualized plan (Section V). The fifth section shows trainees how to design and aid the implementation of an

individualized plan. A fourth case study is provided to give trainees practice with this process.

- Evaluate how a plan is working and make adjustments (Section VI). This final section aids the trainee in learning how to provide ongoing program evaluation and implementing any needed changes.

I. UNDERSTANDING WHAT FETAL ALCOHOL SYNDROME IS AND WHAT IT IS NOT

Terminology

Fetal alcohol syndrome (*FAS*) was first defined as a medical syndrome in 1973 by researchers at the University of Washington in Seattle (Jones & Smith, 1973; Aase, 1981; Little, Asker, Sampson, & Renwick, 1986). A syndrome is a constellation of features related to a common etiology, in this case prenatal alcohol exposure. All of the following items are required for the diagnosis of FAS (Astley & Clarren, 1997):

1. Confirmation of maternal alcohol exposure
2. Evidence of a characteristic pattern of facial anomalies
3. Evidence of growth retardation
4. Evidence of central nervous system (CNS) dysfunction

Other diagnostic categories addressing the existence of alcohol-related CNS damage occur in the absence of either facial abnormalities or marked growth deficiencies (Astley & Clarren, 1997; Stratton et al., 1996):

1. Partial FAS with confirmed maternal alcohol exposure
2. Atypical FAS
3. FAS without confirmed maternal alcohol exposure
4. Alcohol-related birth defects (ARBD), or Sentinel physical findings (a combination of key physical findings highly sensitive and specific to in utero alcohol exposure).
5. Fetal alcohol related conditions (FARC), including
   a) Alcohol-related neurodevelopmental disorder (ARND)
   b) Static encephalopathy (any unchanging physical abnormality in the brain)
   c) Neurobehavioral disorder

It is in the fifth category (FARC) that the majority of clients affected by prenatal alcohol exposure are likely to fall. *Alcohol-related neurodevelopmental disorder (ARND)* may be defined as follows:

> *A history of maternal alcohol exposure, along with CNS abnormalities characteristic of FAS, and/or evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties, deficits in school performance, poor impulse control, problems in social perception, deficits in higher level receptive and expressive language, poor capacity for abstraction or metacognition, specific deficits in mathematical skills, or problems in memory, attention, or judgment (Stratton et al., 1996, p. 5).*

This category is similar to static encephalopathy (Astley & Clarren, 1997, p. 16), fetal alcohol-related conditions (FARC), or the previously used term, fetal alcohol effects (FAE).

Diagnosis

Diagnosis is made by an expert trained in the assessment of birth defects. This can include specially trained physicians such as dysmorphologists, geneticists, pediatricians, neurologists, and obstetricians-gynecologists. Diagnosis should not be made by nurses, psychologists, teachers, vocational or school counselors, or physicians who do not have the training and experience required, because the diagnosis must differentiate between FAS and certain genetic disorders that look similar to it, such as fragile-x syndrome, Aarskog syndrome, Noonan syndrome, and Fetal hydantoin syndrome (Astley & Clarren, 1997, p. 2). For many people, a diagnosis of FAS stigmatizes the birth mother. Therefore, diagnosis is a serious matter, and should be made by a *team* including, but not limited to, the dysmorphologist, an educational expert, a family or community advocate, a psychologist, a social worker, an occupational therapist, a speech and language expert, a public health nurse, and a VR counselor, if the client or student is an adolescent or adult. Each member of the team contributes significant input and, after diagnosis, serves as an advocate, support, and

educational resource for the family. This is particularly important when it comes time for implementation of an individualized service, education, or employment plan.

This team model has been designed and implemented through the University of Washington in Seattle by Dr. Sterling Clarren and Dr. Susan Astley. This team approach is the center of a network of similar clinics being operated around the state of Washington and the United States (Clarren & Astley, 1997). This model is particularly helpful in that it accesses and utilizes resources currently in place in each community. It can also be an excellent guide for identifying where there are service gaps and providing information to community leaders about the best possible method to plug these gaps.

Diagnosis is based on an assessment of the factors outlined above (Astley & Clarren, 1997). In the Astley and Clarren system, each factor is ranked on a 4-point Likert scale and placed on a four-by-four grid. The rank of each area is determined in conjunction with a diagnostic team and standard scores for each area. For example, growth is based on height and weight. Genetic factors, such as parental height, should be considered when determining if a client is truly growth deficient. Weight is adjusted for gender and age and then, based on the standard scores, a number is assigned and placed into the grid. Weight is assessed over the life span of the client. The lower the overall pattern of weight, the higher the score on the grid, e.g., a client who was below the 5th percentile at birth and remains growth deficient would receive a score of 4 on the grid.

Facial abnormalities are assessed through measurements and comparison of the philtrum/upper lip area to a standardized chart. The length of the eye slit (palpebral fissure) and the distance between the eyes is measured. The smaller the eyes and the greater the distance between the eyes, the higher the score for the eye measurement. However, some ethnic groups may have different population standards for palpebral fissures (Stratton et al., 1996, p. 72), and the standards for American Indians and Alaska Natives are not well known. The eye measurement is figured in with the level of

abnormality of the philtrum/upper lip area and assigned a score. This score is placed on the grid.

Evidence of brain (CNS) damage can include lower IQ scores, a small head (microcephaly), or testing results. IQ scores lower than 60, abnormalities on a brain scan or other objective tests, or a persistent pattern of neurologic findings, such as microcephaly or a diagnosed seizure disorder, would rate the client a score of 4 on brain damage.

To obtain a 4 on the grid for alcohol exposure, the client's mother or another reliable informant must confirm maternal prenatal use and report exposure that would produce a blood alcohol concentration greater than 100 mg% weekly, early in the pregnancy (Astley & Clarren, 1997). Lower frequency and amounts would result in a lower score on the grid. A rank of 2 means alcohol exposure unknown, and a rank of 1 means confirmed *absence* of gestational alcohol exposure.

Fours or threes in all of the above categories are required to receive a diagnosis of FAS. There are 256 different diagnostic codes based on this grid system. To be considered for a diagnosis of FARC, there must be evidence of both alcohol exposure and brain damage, e.g. through behavior or testing scores. As other developmental disabilities, personality disorders, and psychiatric disorders can also produce signs of brain damage, FARC cannot be considered a possibility without confirmed prenatal alcohol exposure.

In addition to the four factors outlined above, pre and postnatal trauma other than exposure to alcohol must be taken into account. For example, if a client has been sexually abused, this must be taken as a possible factor in rating the amount and type of CNS damage. If the mother was in a serious car accident prior to the client's birth, this must be taken into account in assessing the physical findings and brain damage. There are many of these factors, some of which will become clear in reading the case studies included in this manual. The Astley-Clarren grid can also be used as a screening and referral tool (see the section on Assessment for more information on this process).

Embryology

The auditory, vestibular, ocular, CNS, and craniofacial systems are tied together embryologically, anatomically, and functionally. Congenital anomalies in one system are generally associated with anomalies in the other systems (Church & Kaltenbach, 1997). Alcohol is a powerful teratogenic (birth defect causing) drug. Organs form during the first 6 to 12 weeks after implantation of an embryo, so that exposure to any teratogen (such as alcohol) during that time can lead to gross structural malformations and other alcohol-related birth defects (ARBD), including the facial features characteristic of FAS. Brain development occurs throughout gestation and past birth. At any point during gestation, after implantation has occurred, the brain can be adversely affected by maternal alcohol consumption. Embryonic cells can be killed by maternally consumed alcohol, and neuronal cell populations may be particularly vulnerable. The brain damage associated with prenatal alcohol exposure is often due to the disruption of brain cell migration as the brain develops. Gross brain structures may be significantly reduced in size, resulting in microcephaly or the reduction in size of specific parts of the brain. Alcohol can impair development of the corpus callosum, the band of connecting tissue between the right and left hemispheres. Ocular and auditory defects are also common. In fact, the presence of a congenital eye anomaly is usually thought to indicate the presence of an inner ear anomaly (Church & Kaltenbach, 1997). For these reasons, hearing and visual impairments are common in people with FAS. The face is also developing at this time, so that daily consumption or heavy binge drinking can impact fetal development, resulting in the classic face seen in FAS and used as part of the diagnostic criteria on the Astley-Clarren grid (see Section III).

Following the stage of organogenesis, toxic exposure to teratogens, instead of producing gross structural malformations, produces histological changes in tissues, inhibits growth, and produces subtle changes in the developing CNS (often manifested as neurobehavioral effects) by interfering with histogenesis, synaptogenesis, neuronal differentiation and migration, the formation of myelin, and so forth (Stratton et al.,

1996, p. 39). These two forms of brain damage (structural malformations and cell-level damage) are the source of the many disabilities associated with FAS and FARC (Streissguth, Clarren, & Jones, 1985; Conry, 1990; Uecker & Nadell, 1996; Stratton et al., 1996) and are involved in the CNS dysfunction that is part of the definition of FAS and FARC.

Most fetal growth occurs in the third trimester. Alcohol consumed in the last trimester can lead to decreased fetal growth, brain damage, or more subtle physical problems. No amount of alcohol has been determined to be safe, and after implantation has occurred, no time during pregnancy is free from risk if alcohol is used by pregnant women.

II. PRIMARY AND SECONDARY DISABILITIES ASSOCIATED WITH FAS AND FARC

Terminology

Brain damage caused by prenatal alcohol exposure cannot be cured, nor can the brain cells killed by alcohol be replaced. The effects of the brain damage can be reduced, and to some extent the brain can be rebuilt by constant repetition to develop new links between cells (synaptogenesis). However, the extent of brain repair in individuals with FAS/FARC has not been adequately studied. Current experience indicates that even with early intervention, brain damage and its associated behaviors are likely to persist across the life span.

This primary condition (brain damage) affects the individual's ability to function. The extent of these effects is determined by how much and when the mother drank during her pregnancy, and by individual characteristics. Associated with this primary condition, there may be comorbidity or co-occurring health conditions, as well as secondary conditions. For example, attention deficit hyperactivity disorder (ADHD) is often associated with FAS. It is a distinct disability that may co-occur with FAS but is not necessarily caused by FAS.

Primary Disability

The VR system defines *primary disability* as the one that is most vocationally handicapping. This is not necessarily the most severe disability. In schools, the primary disability might similarly be identified as the one that is most educationally handicapping.

A primary disability may also be thought of as a disability that one is born with. In the case of FAS, the primary disabilities result from brain damage and, as such, cannot be cured. FAS is generally considered a medical condition and is not recognized per se as a disability. However, FAS may result in one or more recognized disabilities, such as

mental retardation, or learning disability. But the word "primary" is relative: Medical people tend to understand primary as referring to the cause, whereas professionals in VR are more likely to understand primary as referring to the most vocationally handicapping disability.

Disabilities Commonly Associated with FAS/FARC

Although FAS/FARC has been associated with many disabilities, quantitative studies of comorbidity are few. A study of 145 FAS/FARC cases in Alaska (Colberg, 1997) showed that 41% of the cases had speech or language delay, 35% had fine or gross motor delay, 28% had short attention span or attention deficit disorder (ADD), and 20% had learning disability or mental retardation. Most of these 145 cases (83%) were Alaska Natives. Multiple disabilities were common. In another study in Alaska of 36 children with FAS, 34% had a speech impairment, 20% had mental retardation, 20% had learning disabilities, 14% had "pre-school disabilities" (developmental delays), 6% had serious emotional disturbance, and 6% had multiple disabilities (Gessner, Bischoff, Perham-Hester, Chandler, & Middaugh, 1998). Church, Eldis, Blakley, and Bawle (1997) cited a study reporting a high incidence (29%) of hearing impairment due to sensorineural hearing loss (SNHL) in a group of 14 children with FAS. Their own study of 22 FAS patients showed that 27% had mild SNHL, 82% had receptive language deficits, and 73% had expressive language scores more than one standard deviation below the norm for their chronological ages. They concluded that "virtually every FAS patient with a language disorder also had a hearing disorder and vice versa" (p. 231).

Language disorders can impact a person's performance across many aspects of life, and certainly vocational development is no exception. Persons with FAS/FARC may be talkative, but what they say can sometimes seem inappropriate or out of place. They have been described as "talking too much and too fast, but having little to say" (Streissguth, LaDue, & Randels, 1988, p. 31). The capacity for verbal output may exceed their ability to process verbal output: They may find it difficult to absorb and recall a simple list of instructions. However, "careful observation and testing may be able to

illustrate high levels of competence in non-language based problem solving (e.g. Block Design on the WISC-R) and may help to differentiate the language disabled student from the child with Fetal Alcohol Syndrome" (Wegmann, Colfax, Gray, & Reed, 1998, p. 31).

In a much larger sample of persons from the Pacific Northwest, 27% of clients with FAS and 9% of clients with FAE (FARC) had IQs of 70 or below, suggesting the possibility of mental retardation. More than 40% of adults had attention deficit problems and more than 50% had depression problems (Streissguth, Barr, Kogan, & Bookstein, 1996, pp. 20 & 35).

In summary, people who have FAS/FARC are at high risk for speech or language disorders, learning disabilities, hearing impairment, mental retardation, attention deficit disorders (ADD), depression, and other disabilities. However, these disabilities in a person with FAS/FARC often differ in details from the way these disabilities are expressed in persons who do not have FAS/FARC (Wegmann et al., 1998, p. 31). These unique qualities are only beginning to be understood.

Secondary Disabilities/Conditions

In VR, a secondary disability is any disability that is vocationally handicapping but is not the primary disability. In the literature on FAS, secondary conditions are sometimes referred to as "secondary disabilities." They are considered secondary because they develop as the result of a primary condition, i.e., alcohol-induced damage to the brain of the fetus. In VR literature, these secondary disabilities are more likely to be considered as secondary conditions or functional limitations. These are discussed in more detail in the following sections.

The term secondary conditions was coined in 1988 (Marge, 1988) to refer to the additional disabilities (or conditions) that may result from the acquisition of a primary disability (or condition). Several factors help identify a secondary disability/condition:

1. It is associated with and arises from the increased risks created by the primary disability (or condition).

2. It may be just as limiting as the primary disability (or condition) in negatively impacting daily functioning.

3. The secondary disability (or condition) occurs after the acquisition of the primary disability (or condition)—there is usually a lag time or latency period between the recognition of the primary and secondary conditions. In the case of FAS/FARC, the secondary disabilities (or conditions) are often the first recognized.

This dual terminology (disabilities vs. conditions) is the result of shifting emphases within the professions. A secondary disability is distinguished from a comorbid or co-occurring health condition. Streissguth and her colleagues at the University of Washington have used the term "secondary disability" in this context. However, over the past decade or so a number of scientists at the Centers for Disease Control have indicated that interest in this area should not be restricted to secondary disabilities alone but should encompass all health complications that may arise because of the increased risks to health created by the primary disability. Therefore, it has been argued that a better term is "secondary *conditions*" to cover all health complications. At first, this term was intended to refer to physical and mental health issues. Now it also includes behaviors, events, and so forth. Restricted usage of the term "disability" is common in VR, in which the secondary disabilities discussed in the FAS literature would more likely be recognized as secondary conditions.

Thus, "secondary conditions" is the term used in this manual to distinguish a broad array of physical, medical, social, emotional, or familial conditions and limitations to which someone with a primary diagnosis is vulnerable by virtue of that primary condition.

These secondary conditions *can often be treated and remediated*. Individuals with FAS/FARC are at high risk for these secondary conditions, which can be associated with functional limitations. Secondary conditions due to alcohol-related brain damage may include but are not limited to memory problems, difficulties with abstracting abilities, impulsivity, a lack of understanding of cause and effect, poor judgment, and being easily influenced. Psychiatric problems, loss of residential placement, educational

and vocational concerns, legal issues, in both civil and criminal cases, psychosocial problems, and substance abuse are frequently reported in the FAS literature as secondary disabilities associated with prenatal alcohol exposure. For people with FAS/FARC, it is the secondary conditions that most negatively impact gainful employment (For a more in-depth discussion of the secondary disabilities associated with fetal alcohol syndrome, see Streissguth et al., 1996.).

This difference in terminology between secondary disabilities and secondary conditions makes it appear as if the fields of FAS research, on the one hand, and special education and VR on the other hand, often speak different languages. In reality, the fields are far closer than one might think, as we hope to show, and the differences are due at least in part to an evolving terminology. For this training manual, the following terminology is used:

Primary Condition: This is a condition that one is born with that cannot be changed (e.g., FAS or cerebral palsy).

Primary Disability: This is the disability that is most vocationally or educationally handicapping (e.g. mental retardation).

Secondary Condition: This is a condition that one is not born with, but that develops as a product of a primary condition and one's environment. This term is similar to functional limitation.

Secondary Disability: A secondary disability is a barrier to vocational or educational progress, but is not the primary disability.

Functional Limitations

A barrier or deficit that interferes with some predetermined standard of functioning is called a "functional limitation." The standard used in VR programs is past, current, or potential successful vocational performance. The entire development of a VR case hinges on the proper identification of functional limitations at the outset. Functional limitations are a key concept in VR because the services provided under the IPE are directed explicitly at the remediation of these limitations. Functional limitation statements provide a basis for explaining why an individual needs services, why

specific services are planned, and how these services are expected to contribute to the individual's rehabilitation. Similarly, in an educational context, the standard might be past, current, or potential successful *educational* performance. This information is to be used to describe the client when determining eligibility, planning services (such as the IPE), and describing improvement in functioning at closure or at annual performance evaluations.

Specific information about functional limitations that are common among individuals with FAS or FARC are summarized from pages 16-19, along with codes used in the VR system in Arizona (similar systems are in use in other states). An asterisk indicates a functional limitation that identifies a client as severely impaired when both the limitation exists and the individual needs multiple services over an extended period of time [Note: Bulleted capital letters in outline indicate selected items drawn from Arizona's more comprehensive list].

02 - Communication Limitations

- J. Cannot read or speak English [*Note: this assumes an English-speaking home and school environment. Not to be used alone.*]
- K. Lacks communication skills (e.g., deaf person with no knowledge of sign language). People with FAS/FARC have difficulty processing verbal input, so have them repeat back in their own words their understanding of what was just said to see if they processed the information. If they cannot do this, they may lack communication skills or have a speech or language impairment.
- L. Has poor or no interactive skills with other people.

03 - Sensory Limitations

- A. Cannot tolerate loud noises.

04 - Dysfunctional Behavior (Emotional)

Disabilities, and their impact, can often lead to emotional or affective concerns such as a lack of confidence, changes in self-esteem after becoming disabled or recognizing the presence of a disability in one's self, and emotional stress caused by the consequences of the disability. The functional limitations should be identified and steps to ameliorate or decrease these problems should be included in the IEP/IPE. [*When these limitations are the basis of VR intervention they should be identified and considered to be "based on the individual's disability."*] Limitations in this category [Dysfunctional Behavior (Emotional)] include those listed below:

- A. Lacks confidence in ability to work and to (re)enter the labor market.
- B. Unable to deal with the facts of disablement as they relate to taking responsibility for a new life.
- C. Suffers from violent mood swings.
- D. Has difficulty controlling his or her temper.
- E. Has fears or phobias affecting his or her ability to work or live independently.
- F. Suffers from extreme passivity.
- G. Does not relate normally with people (poor social and interpersonal skills).
- H. Is abusive to self or others.

04 - Dysfunctional Behavior (Emotional) - *continued*

- I. Has a low energy level.
- J. Has unrealistic view of self.
- K. Has unrealistic view of the world of work.
- L. Is not in touch with reality.
- M. Has little or no sense of personal identity.
- N. Has low self-esteem.
- O. Is awkward in social settings.
- P. Has not learned basic social or survival skills.
- Q. Cannot handle stress as it relates to everyday living.

06 - Invisible Limitations

- A. Lacks vocational skills [*cannot be used alone*].
- B. Lacks work habits (does not know how to work).
- C. Has knowledge or training in a specific vocational area but lacks the performance skills for job placement.

07 - Restricted Environment

- A. Must be in a controlled environment.
- H. Must avoid an environment with excess noise.
- K. Must be able to move about freely (cannot stay in one position for long periods of time).

08 - Mental Limitations

The limitations in this category encompass intellectual capacity and achievement. Deficits in these areas can seriously impact the client's ability to learn, recall, process, and use information in a positive fashion. Individualized plans should address the possible or actual limitations the client has in each of the following areas and provide for services to reduce the negative impact of such deficits. Limitations in this category include those listed below:

- A. Impaired ability to learn in one or more areas.

08 – Mental Limitations (*continued*)
• B. Impaired ability to understand in one or more areas. • C. Impaired reasoning ability. • D. Difficulty processing new information. • E. Unable to remember information. • F. Unable to make change [money]. • G. Unable to learn basic social or survival skills. • H. Can only follow 1 or 2 step directions. • I. Requires ongoing and supportive supervision. • J. *Lack of ability to work independently (and multiple services are needed over an extended period of time). Documentation of the effects of the impairment can be made by medical, psychological, or vocational evidence.

09 - Substance Dependency
• B. Physical dependency (addiction) to drugs.

11 - Consciousness Limitation
• B. Has periods of involuntary inattentiveness.

13 - Debilitation or Exertion Limitation
• D. *Lack of ability to work independently (and multiple services are needed over an extended period of time). Documentation of the effects of the impairment can be made by medical, psychological, or vocational evidence.

14 - Motivity Limitation
• E. Cannot sit still (hyperactive) or rocks back and forth. • F. Has impaired motor functioning due to medication. • I. Movement speed is restricted to noncompetitive level.

15 - Educational Skills (in English)
• A. Does not read.
• B. Has survival skills in reading (2nd grade and below).
• C. Reads and understands basic instructions only (3rd grade - 5th grade).
• D. Does not have usable writing skills.
• E. Has limited writing skills (3rd grade - 5th grade).
• F. Does not add or subtract.

Listed below are other attributes that may functionally limit the client's employability due to others' perceptions and concerns. These may not actually restrict the client's ability to work or function, but nonetheless may constitute employment limitations requiring special counseling or intervention and placement assistance. Eligibility for VR services is NEVER based upon the following:

- Unstable or nonexistent work history
- Criminal record
- Minority group identification
- Socioeconomic identification
- Socially unacceptable appearance, e.g. poor hygiene

These additional attributes are commonly observed in clients with FAS and FARC. They are also items that may be functionally limiting, *but only because others consider them as such.* In VR, they might be considered as secondary conditions imposed by persons who are not aware of the client's disabilities.

A client may present with only a few functional limitations. However, in reality, many may exist. It is these deficits that vocational programs must adequately address to aid in acquiring and maintaining gainful employment for clients with FAS/FARC. In

the parlance of FAS/FARC, the functional limitations itemized in this section are consistent with what some have considered as secondary disabilities.

The Need for Vocational Rehabilitation

People who have FAS/FARC are at high risk for problems with employment (PWE) and for being unable to live independently when they become adults. These are two of the secondary disabilities defined by Streissguth et al. (1996) on the basis of 90 cases (actual sample size may be slightly less for some categories). A majority, 79% of the men and women in their sample had a history of PWE. The researchers defined PWE using a number of criteria, including: (a) having financial support other than their own earnings, (b) earning less than $280 per week, (c) being in a sheltered workshop, (d) working half time or less, or (e) having had more than three jobs over the past two years. Each of these were regarded as red flags indicating PWE. Even though low IQ was not an explicit factor, every person with FAS/FARC who had an IQ of 70 or below also had PWE. Among those defined as having PWE, almost two-thirds had problems holding a job, half had trouble getting hired, half had experienced being fired, and almost one third had lost a job without understanding why. The most common on-the-job problem was being easily frustrated (65%), followed by poor task comprehension (57%), poor judgment (55%), and social problems (54%). At least one of these (poor task comprehension) may indicate poor job placement.

Streissguth and Barr (1998) conducted a similar study of the American Indians in their data, consisting of 53 Native Americans who were 14 to 51 years old. Twenty four (24) of these were at least 21 years old. In this sample, 87% had PWE. However, 83% had been employed for wages. Holding a job for more than 2 years was rare; most held their job for between 4 and 24 months. The same problems were observed as for the general population, but with percentages 5–10 points greater. Virtually all adult clients in this sample had an unstable relationship to the work environment.

III. SCREENING AND FUNCTIONAL ASSESSMENT

Screening for FAS and FARC is something any trained professional can do. A number of tools are discussed in this section. None of them have been validated specifically for American Indians.

FASNET Assessment Tool

The FASNET Assessment Tool for Use With Adults (Berg, Kinsey, Lutke, & Wheway, 1995) was developed to help parents and professionals (a) acquire a comprehensive and nonmedical method of assessing whether prenatal alcohol exposure is a factor in difficulties any particular individual might be displaying; (b) determine if a diagnostic evaluation is warranted; (c) help provide information to the family physician; (d) translate medical jargon into lay terms; and (e) facilitate understanding and communication between parents, caregivers, and providers.

An advantage of the FASNET is that it is a screening instrument specifically designed and scored for FAS screening by nonprofessionals. The areas covered by the FASNET include a history of prenatal alcohol exposure; developmental history; school history; physical findings; communication and language usage; social skills; overall behavior; attention, activity, and impulsivity; memory; cognition; safety issues; and mental health issues. This checklist has 265 items; a score of more than 50% indicates the need for a physician referral in order to assess the *possibility* that alcohol-related birth defects are playing a part in the developmental or behavioral problems of this child. The checklists on safety issues and mental health issues are provided, but are not used in the scoring. A different FASNET assessment tool has been designed for teenagers, ages 14–18.

Astley-Clarren Grid

This grid (Figure 1) was developed by Drs. Susan Astley and Sterling Clarren (1997) to aid in diagnosis, as described in the section, Diagnosis. When used for screening, it

should include information from the areas of growth deficiency, facial features, brain dysfunction, and gestational alcohol. In screening, we will attempt to rate the level of risk for each of these four risk factors on a scale from 1 (no risk) to 4 (high risk). Counselors doing the screening should base the information on either standard scores or their best guess. If there is a question about the presence of any one area, the lower risk level should be marked with a referral for further assessment.

For example, if there is a "moderate" growth deficiency, that cell is marked with a 3, an X, or a check ✓ (Figure 2). The 3 indicated in the left margin of the corresponding row translates to the 3 written below the column, as shown in Figure 2. In this sample case, the individual is rated as having "moderate" facial features associated with prenatal alcohol exposure, "definite" brain dysfunction, and "high risk" for gestational alcohol. When the grid has been filled in (Figure 2, top rows), this can be converted to a numeric four-digit code (bottom row) and used as part of the referral information provided to the dysmorphologist and other providers. But this referral information is only guesswork. Only a dysmorphologist, geneticist, or specially trained physician can determine the severity of facial features.

Figure 1. The Astley-Clarren Grid.

Rating	Growth Deficiency	FAS Facial Features	Brain Dysfunction	Gestational Alcohol
(4)	significant	severe	definite	high risk
(3)	moderate	moderate	probable	some risk
(2)	mild	mild	possible	unknown
(1)	none	absent	unlikely	no risk

Figure 2. Sample Case Using the Astley-Clarren Grid.

Rating	Growth deficiency	FAS Facial Features	Brain Dysfunction	Gestational Alcohol
(4)			✓	✓
(3)	✓	✓		
(2)				
(1)				
Sample Case =	*3*	*3*	*4*	*4*

The Astley-Clarren grid is being used, in this context, only for screening purposes. If there is definite (4) or postulated (3) prenatal alcohol exposure, along with any of the limitations previously described, it is important to refer the client for a more extensive diagnostic evaluation.

Rating the Facial Features

As explained in the section, Diagnosis, assessment of FAS facial characteristics is based on (a) a thin upper lip, (b) a smooth philtrum (upper lip area), and (c) small eyes that appear to be widely spaced. In a diagnostic evaluation, these features are measured and evaluated in a complex process (Astley & Clarren, 1997, pp. 23–26), because the degree to which each feature is expressed varies from severe (extreme classic form) to absent. These features are best evaluated with a full-face photo taken between the ages of 2 and 12 with a neutral facial expression, as smiles and other facial expressions can distort these features. Family standards, especially for a thin upper lip, should be taken into consideration, as normal upper lip thinness varies from one family and race to another. For screening purposes, one should take as much care as is feasible to avoid overdiagnosing. To receive a 4 rating, all three features must be unmistakably present in severe form. To receive a 3 rating, two of the three must be present in severe form, and the third must be present in moderate form.

Rating Growth Deficiency

Growth deficiency must take family norms into account, as well as age-appropriate standards, gender, and postnatal environmental influences. Records of an individual's growth history are very important because by adulthood, infant growth deficiencies may be obscured by environmental influences. Thus, for diagnostic evaluation, rating growth deficiency can be quite complex (Astley & Clarren, 1997, pp. 19–22). For a 4 rating, there should be evidence of severe growth retardation in both height and weight after controlling for parental height and postnatal environmental influences. For a 3 rating, at least one of the two should be severe and the other should be moderate.

Rating Gestational Alcohol

Typical questions regarding gestational alcohol are included in the FASNET General Information section (Berg et al., 1995; see also Wegmann et al., 1998). Other good questions can be found in Streissguth (1997, Figure 2.2, p. 21). To obtain a 4 on the grid for alcohol exposure, the client's mother or another reliable informant must confirm maternal prenatal use and report exposure that would produce a blood alcohol concentration greater than 100 mg% weekly, early on in the pregnancy (Astley & Clarren, 1997). Lower frequency and amounts would result in a lower score on the grid. A rating of 3 is given when drinking occurred during gestation in frequencies and volumes less than that for a rating of 4 *and* the source of the report is the birth mother, a direct observer, or some other reliable source. A rating of 2 means "alcohol exposure unknown," whereas a rank of 1 means "confirmed *absence* of gestational alcohol exposure."

Rating Brain Dysfunction

A number of instruments are presented here for evaluating brain dysfunction. A 4 rating requires one of the following:

1. Evidence of mental retardation (a diagnosis, or IQ < 60).

2. Structural anomalies of the brain on CT/MRI, such as partial or complete agenesis of the corpus callosum, cerebellar hypoplasia.

3. Microcephaly (small head circumference for age or gender).

4. Neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, or poor eye-hand coordination if extra-neurological causes for these signs can be ruled out.

If evidence for the above is lacking, the instruments described in the following pages can help decide whether to rate brain dysfunction as a 1, 2, or 3 in the Astley-Clarren system.

Functional Indicators of Organic Brain Dysfunction

Wegmann et al. (1997) have also published a checklist of functional indicators of organic brain dysfunction for adolescents and adults based on Astley and Clarren (1997, p. 8). This two-page checklist contains 55 items in eight categories that are to be answered *Yes, No, Unknown*, or *Too Young to Assess*. A sufficient number of these items serves to support a category 3 classification in the grid for brain dysfunction. However, as Astley and Clarren note, "to date, criteria for the number of deficiencies that must be present to warrant a Category 3 classification have not been established" (p. 27).

Fetal Alcohol Behaviors Scale (FABS)

The variables in this checklist have been defined by Streissguth, Bookstein, Barr, Press, and Sampson (1998). The 36 items involved are a condensed version of their earlier 68-item Personal Behaviors Checklist (PBC). Thus, the items are weighted heavily toward the Brain Dysfunction component of FAS, and only indirectly to the factors of facial dysmorphology, growth retardation, or maternal alcohol consumption. Nevertheless, it is a screening tool that can be interpreted for FAS/FARC screening in a straightforward manner. As with most checklists, each item usually invites a *Yes* or *No* response. On average, they report that it takes about 5 minutes to complete. The FABS is inexpensive to administer and score, and the summary score appears to be

independent of age, sex, race, IQ, and FAS versus FAE. It shows promise of being a suitable screening tool when combined with a few other relevant questions, making it potentially very useful as a screening device. Unfortunately, the FABS is not available to the public at this time, except by special arrangement with the authors.

The items are intended to be asked of the person's caretaker. According to the authors, a Yes on 15 or more of the 36 FABS items indicates that the person is at risk for FAS or FARC, and that a more thorough assessment and diagnosis is needed. When the same items were administered on a normal population, most had no more than 10 Yes responses. Its maximum usefulness applies across various groups from age 2 through age 35.

Fetal Alcohol Exposure Risk Assessment For Adolescents And Adults

The items in this screening instrument (Appendix A) are closely related to the criteria used to define FAS. The items are intended to be obtained mostly from existing case history files. When no information exists in the files with respect to a particular item, it may be left blank. If appropriate, other information sources can be sought. This screening instrument has not yet been validated by field-testing. No scoring system to minimize false positive and false negatives has yet been established, and this instrument is still experimental. Each of the four diagnostic areas is rated on a four point Likert scale. If these ratings are added together, the minimum score, 4, would be an indication that FAS/FARC is extremely unlikely. The maximum score, 16, would be an indication that FAS is very likely, but that a referral for evaluation should still be made to make sure that the symptoms are not related to some other cause. In terms of the Astley-Clarren grid, a score of 12 or more would serve to support a strong recommendation for referral for evaluation. In this sense, it is a tool that can be used for FAS/FARC screening on an experimental basis. The authors invite those who might use this instrument to share their results with us so that a better scoring system for referral that minimizes false negatives and false positives can be established.

Adaptive Behavior Assessment

Adaptive behaviors are everyday skills such as walking, talking, getting dressed, going to school and work, preparing a meal, cleaning the house, and so forth. They are skills that a person learns in the process of adapting to his or her surroundings. Because adaptive behaviors are for the most part developmental, it is possible to describe a person's adaptive behavior as an age-equivalent score. An average five-year-old, for example, would be expected to have adaptive behaviors similar to those of other five-year-olds.

Behavior problems, often called maladaptive behaviors, are those that interfere with everyday activities. Good adaptive behavior and a lack of behavior problems promote independence at home, at school, and in the community. Behavior problems are far more difficult to quantify than adaptive behaviors because they are not developmental and their expression varies from day to day and from setting to setting. Behavior problems do not increase or decrease steadily with age. Nevertheless, they can be reliably measured.

The purpose of measuring adaptive and maladaptive behavior is usually either for diagnosis or for program planning. The diagnosis of mental retardation, as an example, requires deficits in both cognitive ability and adaptive behavior, occurring before age 18. Adaptive behavior assessment is also used to determine the type and amount of special assistance that people with disabilities may need. This assistance might be in the form of special education and vocational training for young people, and supported work or special living arrangements such as personal care attendants, group homes, or nursing homes for adults. Adaptive behavior assessments are often used in preschool and special education programs for determining eligibility, for program planning, and for assessing outcomes.

The Vineland Adaptive Behavior Scales (VABS), a revision of the original Vineland Social Maturity Scale, are distinguished by their heritage as well as by good norms and psychometrics (Sparrow, Balla, & Cicchetti, 1984). The VABS assesses personal and

social skills, with norms up to age 18. Two interview editions, one with 577 items, the other with 279 items, gather information through semistructured interviews with a parent or caregiver. Both include a Motor Skills Domain for children less than 6 years old and an optional Maladaptive Behavior Domain for children 5 to 18. There is also a 244-item Classroom Edition completed by a teacher.

The VABS is administered by a psychologist, social worker, or other professional with a graduate degree and training in interview techniques. Although the assessment booklets are straightforward and well organized, the interview process is complex and time consuming. Completion of the VABS is accomplished through asking general questions with additional probing as needed. The respondent is not asked the questions directly nor allowed to read the actual questions.

A similarly administered behavior section contains a list of 27 minor maladaptive behaviors, e.g. sucking the thumb or fingers. Nine more serious behaviors, not normed for nonhandicapped individuals, can be scored by both frequency and severity (Hill, 1998). The VABS covers five areas: communication skills, daily living skills, socialization, motor skills, and maladaptive behaviors. The motor skills domain is only for children under 6 years of age. The communication domain includes receptive, expressive, and written communication skills. Daily living skills encompass personal, domestic, and community interactions. The socialization domain includes interpersonal relationships, play and leisure time, and coping skills.

All of these are scored and the average of these scores is used as the Adaptive Behavior Composite. These scores are translated into standard scores and into age equivalents. This gives a comparison of the client's skills to their age mates. The Adaptive Behavior Composite score can be used to screen for FAS: A composite score of less than 65 indicates that the person may be at risk for FAS/FARC (Streissguth et al., 1996, p. 26) and that referral for FAS/FARC diagnosis is warranted. However, some children with a higher composite score can have FAS/FARC, especially if there is evidence of maternal alcohol consumption during the pregnancy.

The Maladaptive Behavior Scale concerns specific behaviors that are often correlated with organic brain damage or psychiatric disorders. It should be noted that, once again, the areas covered on the VABS correlate well to those on the FASNET, the Astley-Clarren grid, and the information needed for the VR assessment.

The Scales of Independent Behavior, Revised (SIB-R; revised in 1996) is distinguished by several features. It contains an excellent behavior problem scale in addition to its adaptive behavior assessment. It also provides a unique score that reflects overall independence based on adaptive and maladaptive behavior combined. It has norms that extend beyond adolescence—from 3 months to more than 80 years, which makes it more suitable for adult populations than the Vineland. It can be administered either as a questionnaire or as a carefully structured interview, with special materials to aid the interview process. It has a short form, a short form for children, and a short form adapted for individuals who are blind (Hill, 1998).

The SIB-R's 259 adaptive behavior items comprise 14 subscales grouped into four clusters: Motor Skills, Social Interaction and Communication Skills, Personal Living Skills, and Community Living Skills. Each SIB-R adaptive behavior item is a statement of a task (for example: washes, rinses, and dries hair). A respondent rates the individual being assessed each task, using a scale from 0 to 3:

0. Never or rarely performs the task (even if asked).
1. Does the task, but not well, or about one-fourth of the time (may need to be asked).
2. Does the task fairly well, or about three-fourths of the time (may need to be asked).
3. Does the task very well always or almost always (without being asked).

This scale assesses the quality of performance and the individual's motivation. That is, even though someone may be able to perform a task, he or she may not do so independently, either because he does not realize that it is necessary to do so, or because he refuses to (a behavior problem).

The SIB-R measures independence—not just adaptive behavior. Children and adults with developmental disabilities often need special assistance at home, at school, or at work. The SIB-R assesses adaptive and maladaptive behavior to determine the type and amount of special assistance that people with disabilities may need. This assistance might be in the form of special education and vocational training for young people, and supported work or special living arrangements such as personal care attendants, group homes, or nursing homes for adults.

The SIB-R is widely used in special education programs for diagnosis and for determining eligibility, for program planning, and for assessing outcomes. A new SIB-R checklist booklet can be completed by a teacher, psychologist, or social worker directly, or with the help of special interview materials that involve parents. The SIB-R was designed to be an integral part of interdisciplinary planning. Its contents provide an excellent outline for team discussion, often eliciting information and opinions that parents might not otherwise bring up on their own.

Independence is the ability to do things on one's own without getting into trouble. This means not only the ability to perform a task, but also knowing when to do it and having the willingness to do it. Behavior problems interfere with independence, requiring special supervision or restrictions of some kind, and additional assistance with behaving more appropriately. The SIB-R can measure overall independence because, unlike other adaptive behavior scales, it includes a highly reliable measure of behavior problems. Independence is reflected in a Support Score, ranging from 0 to 100, that indicates the service intensity required by an individual, considering both adaptive and maladaptive behavior. A severely handicapped student with many serious problem behaviors would require intensive supervision (a Support Score below 20). A nonhandicapped adult with no behavior problems can live independently without supervision (a Support Score of about 90 or more).

The Support Score was developed with the knowledge that neither adaptive behavior nor problem behavior alone can predict "difficulty." An individual may require close supervision or intense assistance because he or she is severely disabled

(limited adaptive behavior) or simply because he or she is young. Someone with advanced adaptive skills may require even closer supervision (e.g. a higher teacher-student ratio in the classroom) because of serious problem behaviors.

The Support Score was derived to reflect the level of care, supervision, or training needed by individuals at home or in educational and human service programs. Although not a simple formula, the Support Score is a weighted combination of approximately 70% adaptive behavior and 30% maladaptive behavior. This score is able to differentiate not only level of placement, such as regular classroom or special classroom, but also level of success within a classroom or a group home, and even one's rank among one's peers (SIB-R User's Group Home Page, 1998). The primary concern with the SIB-R is that no scoring system is known specifically for persons with FAS/FARC, so that its use for screening must be considered experimental. However, the results may be quite useful for VR counselors and other professionals apart from the issue of FAS/FARC screening.

IV. DEVELOPING AN INDIVIDUALIZED PLAN

This section introduces information that can be used as is, or that can be modified, in writing an individualized plan such as an Individualized Educational Program (IEP), Individualized Service Plan (ISP), or Individualized Plan For Employment (IPE). This information may also be helpful for providing suggestions in program implementation.

An individualized plan has the following purposes:

- Identify individual strengths and deficits of any particular client or student.
- Establish goals consistent with his or her interests and abilities, vocational training, and past work experience (if any).
- Develop a plan to address the deficits and develop the strengths.
- Implement this plan in a timely fashion.
- Produce measurable outcomes that assess the success of the plan.

Person-Centered Planning

Person-centered planning (PCP) refers to several approaches to organizing and guiding individual and community change in collaboration with individuals with disabilities, their families, and their friends. Family-centered planning (FCP) refers to principles designed to lead to partnership and collaboration between parents and professionals to ensure the best possible supports and services for a child with a disability and the child's entire family. Some examples of approaches that use the principles of person-centered planning or family-centered planning are whole life planning, personal futures planning, making action plans (MAPS), planning alternative tomorrows with hope (PATH), individual family service plan (IFSP), and essential lifestyles planning (Marone, Hoff, & Helm, 1997). Although individually distinctive, the foundations for these approaches are based on the PCP/FCP principles of *community presence, choice, competence, respect,* and *community participation.* The steps involved in PCP begin by gathering background information:

1. Develop a history or personal life story of the focus person. This is accomplished by everyone sharing past events in the person's life. The focus person's parents and family may share the largest amount of this information. Things such as background, critical events, medical issues, major developments, important relationships, and so forth, may be shared.

2. Describe the quality of the focus person's life. This may be accomplished by exploring community participation, community presence, choices or rights, respect, and competence.

3. Identify the personal preferences of the focus person—things the focus person enjoys doing and things that are undesirable to the person.

After the background information has been gathered, the next steps relate to the planning meeting.

4. Review the personal profile. The group at this point has the opportunity to make additional comments and observations, as well as adding test results.

5. Review trends in the environment. Identify ongoing events that are likely to affect the focus person's life.

6. Share visions for the future. Through brainstorming, participants are challenged to imagine ways to increase opportunities.

7. Identify obstacles and opportunities—things that could make the vision a reality.

8. Identify strategies and action steps for implementing the vision.

9. Get started; identify action steps that can be completed within a short time.

10. Identify the need for service delivery to be more responsive to individual needs.

Identifying Data

This section of the individualized plan should provide a minimal amount of identifying data, such as date of birth, gender, race or cultural status, and marital status. The referent should be identified and the concerns of the referent, along with any identified by the client.

Diagnoses

This section should simply list any known diagnoses that the client or the evaluator may wish to have ruled out, as well as suspected diagnoses at referral. This includes any relevant medical diagnoses, as well as any professional assessment of disabilities such as learning disabilities, ADD, mental retardation, hearing impairment, visual impairment, and so forth, along with a DSM-IV multi-axial assessment, if available. In addition, screening results [such as the FASNET assessment tool, FABS, and Fetal Alcohol Exposure Risk Assesment For Adolescents And Adults (Appendix A)] should be included. Any information on the Astley-Clarren grid should be provided, along with an indication of whether the information was provided as part of a diagnosis or a screening.

Background Information

This section should include information of the kinds indicated for person-centered planning (personal life story, quality of life assessment, personal preferences), the history contained in the FASNET assessment tool, and any other relevant history. Legal issues, medications, past employment history, relevant medical history, substance abuse history, and legal issues should be covered in this section. This section should include a description of the client's overall appearance, general affect, and ability to attend and follow directions, as well as any observable deficits, such as language problems, memory problems, or high or low activity levels.

Assessment Instruments Administered and Results

This section should provide a listing of any assessment tools (apart from those already used in diagnosis) administered (e.g., IQ, VABS, SIB-R, achievement tests, aptitude tests, career planning results) and the client's or student's scores or performance on these tools. A narrative description of the client's strengths and deficits, based on each tool, is included. The date of administration of each assessment tool should also be included, as scores may change with age. Many commonly used

tests have not been validated specifically for American Indians and Alaska Natives and some are more culture-bound than others. Information about ethnic background should be included in order to keep these test results in perspective and to address possible cultural issues.

Planning Considerations

In this section, planning considerations suggested in the PCP approach should be summarized. These include environmental trends (ongoing events that are likely to affect the focus person's life), visions for the future (brainstorming), obstacles, and opportunities. Environmental trends might include changes in eligibility for services, transition from one status to another (e.g., school to work transition), expiration of support services, and so forth. Changes in family relationships involving parents, significant others, siblings, or children should also be reviewed. Visions for the future might include career opportunities and vocational planning, desired place of residence (such as reservation, American Indian community, urban area), desired residential setting (living independently, with family members, or in a suitable residential facility), and desired natural support networks (such as family, Indian organizations, or religious organizations).

Summary and Recommendations

This section is a summation of the information in the previous sections. A review of the client's concerns and needs is included. In addition, this section provides recommendations to (a) address the deficits noted, (b) identify resources in the community for vocational training and placement, and (c) make further referrals and evaluations if warranted.

This section should be clear, concise, and practical. It is intended to be the road map for providers, caregivers, and vocational training people to work from when developing and implementing an individualized plan. Specific names of programs and providers should be included if at all possible.

Case Studies

We are now ready to use this information to consider an actual case study. Certain aspects of each case have been changed to preserve anonymity. Each case study is based on an individual of American Indian birth or heritage. The purpose of this case study is to illustrate some of the concerns facing American Indians with FAS/FARC. Trainees are asked to discuss this case in a small professionally diverse group and to respond to the questions listed at the end of the case. The answers are then discussed with the trainer.

Exercise: Case Study #1: Andrea K.

Andrea K. is a 14-year-old girl of Native and African-American descent. She was born to a 19-year-old woman who was living on a small rural reservation. Mrs. K. had a history of substance abuse going back at least 5 years. She traveled back and forth to the nearest urban center, about 50 miles away, where she was involved in prostitution and other criminal activity. It is believed that Andrea is the child of one of Mrs. K.'s customers.

Mrs. K. often left her daughter with family members, many of whom were also involved in substance use. It is documented that she was physically and sexually abused multiple times by multiple people before the age of 5. During one of her outings on the street when Mrs. K. had Andrea with her, she was arrested for prostitution and Andrea was placed into nonrelative, non-Native foster care with a single woman and her 10-year-old daughter.

After Mrs. K. was released from jail, she attempted to regain custody of her daughter. She was ordered by the court to get a psychological evaluation, complete substance abuse treatment, and refrain from any participation in prostitution. Mrs. K. tried several times to complete what had been required but was unable to successfully maintain her sobriety. When Andrea was 7 years old, her mother was diagnosed with HIV/AIDS. She committed suicide by overdose within a month of receiving her diagnosis.

Andrea had been in foster care for 2 years by the time of her mother's suicide. The foster mother asked to adopt Andrea and the tribe wherein Andrea was enrolled agreed. This was accomplished within the next year. Shortly after the adoption was completed, her adoptive mother, Mrs. J., remarried. In the 2 years that she had been with Mrs. J., Andrea displayed significant sexually aggressive behavior, impulsivity,

lying, stealing, and violent outbursts. Andrea was able to bond with her adoptive sister and father but not her adoptive mother. This became a source of tension in the family.

Andrea entered school and was placed into a class for severely behaviorally disturbed children. She was able to maintain her behavior while in the classroom and actually did fairly well on her school work, achieving B's and C's. However, during recess and at home, Andrea's behavior would rapidly deteriorate to the point where her adoptive family began to fear for their own safety. Andrea was placed in therapy but refused to cooperate. Several attempts were made to find a medication that would help but Andrea refused to take these. She molested at least 6 younger children.

The family requested and received a full-time in-home aide to help with Andrea. Andrea's behavior at home was aggressive toward the aides, resulting in rapid staff turn-over. By the time she was 12, her behavior was such that the adoptive mother refused to keep her in the home anymore, contacted the tribe, and asked that the adoption be declared a failure.

Andrea was placed into a group home where she was the youngest child. She received 24-hour-a-day monitoring and structure. Her adoptive father and sister continued visitation but her adoptive mother refused to do so. Andrea's violent behavior continued and she assaulted both the house staff and other group home residents. She refused to participate in therapy, her hygiene deteriorated to the point where Andrea was refusing to bathe, and she began to express having had hallucinations.

The group home staff believed that they could not provide adequate care for Andrea and she was transferred to a long-term child assessment and treatment facility. She has resided in this facility for 8 months and attempts are now being made to place Andrea back in the community. Andrea, while in the hospital, became more compliant with medication and was prescribed Tegretol and Paxil. Her violent behavior has decreased to some degree but she still displays sexually inappropriate behavior and refuses therapy. Andrea, at the age of 14, was 5' 3" tall and weighed 145 pounds.

Andrea was assessed at age 14 at the time of her hospital admission.

Wechsler Intelligence Scale for Children (WISC-III)	
Subscale	Score
VIQ	85
PIQ	101
FSIQ	96

Wide Range Achievement Test-3 (WRAT-3)		
	SS	GE
Reading	98	8th
Spelling	94	7th
Arithmetic	75	4th

Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
Communication	80	9.0 years
Daily Living Skills	95	12.8 years
Socialization Skills	50	5.5 years
Adaptive Behavior Composite	71	8.9 years

Questions:

1. Based on the Astley-Clarren diagnostic grid, what 4-digit code best fits this data? What further information, if any, would be required to make a diagnosis?
2. What disabilities does Andrea probably have? Are any additional assessments needed to identify her disabilities?
3. What are the predominant issues that are of concern in making Andrea's transition from the hospital back to the school and community?
4. If Andrea were to be returned to the school system, what types of professionals should be involved on her IEP team?
5. What types of services will Andrea need in the near future and for her long-term functioning? What types of professionals should be involved?

Special Considerations for Different Individualized Plans

While individualized plans have many common features, they have distinctive characteristics, too. We will proceed chronologically by age of first use, because each may build on the one before. Thus, we begin with a discussion of Individualized Service Plans (ISPs), which may be formulated as early as the preschool years. Individualized Education Plans (IEPs) are discussed next, because they are formulated during childhood or adolescence. Individualized Plans for Employment (IPEs) are discussed last because they are usually developed later.

ISP: Special Considerations

An individualized service plan (ISP) is developed annually and is reviewed biannually, quarterly, or as needed for individuals who have been deemed eligible for services from the Department of Economic Security (DES), Division of Developmental Disabilities (DDD). The ISP is a written statement, developed by an interdisciplinary team (ISP team), of services to be provided and goals and objectives to be attained for a person with developmental disabilities. The ISP directs the provision of safe, secure, and dependable active treatment in areas that are necessary for individuals to achieve full social inclusion, independence, and personal and economic well being.

The ISP team must include, but is not limited to, the eligible individual, his or her parent or guardian, if any, and the DES/DDD support coordinator. The team should also include friends, teachers, physicians, therapists, vocational counselors, direct care providers, and others, as the team deems necessary. The following items are the responsibility of the DDD support coordinator:

- Identify team members and schedule meetings of the interdisciplinary team.
- Notify team members and facilitate meetings (unless contrary to the wishes of the individual or his or her family).
- Write the ISP based on consensus reached during the team meeting.

- Distribute copies of the completed ISP to the team members.

The need for service provision is determined by the ISP team based on formal and informal evaluations and assessments, the preferences of the individual and family or responsible person, and a written statement of the person's goals and desired future. The annual ISP paperwork should include the following sections (Division of Developmental Disabilites, 1993, Chapter 800, pg. 800 - 825):

- ISP Cover Sheet (DD-214)
- Service Plan (DD-215)
- Summary of Professional Evaluations (DD-216)
- Team Assessment Summary (DD-217)
- Preferences and Vision of the Future (DD-218)
- Long Term Goal and Implementation of Goal (DD-219)
- Team Agreements and Assignments (DD-219)
- Support Information (DD-220-1)

The progression of the ISP paperwork is designed to establish the need for services (resources or supports) based on information derived from the functional statements of need, the long-term goal(s), and the objectives. Thus, services are provided in accordance with the individual's needs and objectives to achieve the long-term goal set forth at the planning meeting. For example, if a team identified employment as a goal, an individualized goal would be established based on the current need for skills. The needs would then be addressed by an employment-related program (ERP), which is a service provided by the Division of Developmental Disabilities to facilitate the attainment of prevocational skills necessary to function in a work setting. These skills would then be translated into measurable objectives that allow for individualized teaching strategies and review of progress made by the individual toward the goal. The objectives are then reviewed and modified, during subsequent ISP meetings, until the skills are attained. At this point, a referral would be made to Rehabilitation Services

Administration (RSA) to provide an appropriate vocational placement and related services, such as job coaching.

Exercise: Case Study #2: Gerry G.

Gerry G. is a 17-year-old male of Native descent. He was the only child born to a man and a woman, both of whom were described as alcoholic and both of whom were killed in a single car crash when Gerry was 3 years old. He was placed in an adoptive home with five other younger adoptive siblings. Gerry had a history of mild behavioral problems that were managed by his parents using schedules, clear, concrete, and immediate positive and negative consequences, and a level system where Gerry could earn his privileges.

Gerry was in special education programs and did well in these because the same type of structure was used in both his home and his school environment. He participated in Special Olympic programs and, overall, was doing well until the age of 13, when his behavior began to deteriorate. At this time, two of Gerry's younger female siblings disclosed that he had sexually molested them several times in the past 6 months. Gerry also began to show severely violent behavior and to act out in school. His foster family, in order to protect his siblings, had Gerry placed into a group home.

He resided in this group home with constant supervision and monitoring, and his sexually aggressive behavior was contained. However, his acting out in school, poor impulse control, lying, stealing, and instigating behavior, while it decreased, still remained of concern. Gerry was placed in therapy for sexually aggressive youths and participated, albeit reluctantly. He was able to be transitioned to a foster home with a single male and one other boy. However, the foster father in this home did not provide adequate supervision and structure. Due to serious concerns about Gerry's safety, he was returned to his original group home.

Gerry has had two legal charges placed against him, one for setting a fire to a garbage can at his group home and another for painting gang-related graffiti on a store near his group home. He served 3 months in detention for the first charge and has yet to be sentenced on the second. Gerry is approaching his eighteenth birthday. He has not had any reported sexual offending in the past 3 years, and since the store vandalism 2 months ago, he has not displayed any physically or verbally aggressive behavior. Therapy has continued and, at this point, Gerry is a far more active participant.

A physical examination and a psychological evaluation were done when Gerry turned 17 to help in transitioning to adult services. Gerry measured 5' 8" and 135 pounds at age 17. He has an odd appearance to his face, a frequent source of teasing by the other residents in his group home. (Testing at age 17.)

Wechsler Adult Intelligence Scale-III (WAIS-III)	
Subscale	Score
VIQ	45
PIQ	62
FSIQ	56

Wide Range Achievement Test-3 (WRAT-3)		
	SS	GE
Reading	60	4
Spelling	50	<3
Arithmetic	45	<3

Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
Communication	65	7.2 years
Daily Living Skills	76	8.1 years
Socialization Skills	55	6.5 years
Adaptive Behavior Composite	62	7.2 years

Questions:

1. Plot Gerry's scores on the grid and identify what additional data might be needed to make an accurate diagnosis for FAS/FARC.
2. What disabilities is Gerry known to have? Are there other disabilities he should be assessed for?
3. What type of therapy has Gerry most likely been involved in? What type of approaches might be most useful?
4. What type of vocational rehabilitation and other services is Gerry likely to need?
5. Is he a viable candidate for independent living? Tell what your answer is based on.
6. Is Gerry still a risk to the community? If so, what areas, and what services, if any, might be needed to reduce this risk?

IEP: Special Considerations

An individualized education plan (IEP) is a written statement for each student with a disability that includes, among other things, the following items:

1. A statement of the student's present levels of educational performance, including how the student's disability affects the student's involvement and progress in the general curriculum.

2. A statement of measurable annual goals, including benchmarks or short-term objectives, and how the student's progress towards these goals will be measured.

3. A statement of the services and supplementary aids to be provided to the student, or on behalf of the student, and a statement of the program modifications or supports for school personnel that will be provided for the student.

4. A statement of the extent, if any, to which the student will *not* participate with nondisabled children in the regular class and in other activities.

5. A statement about transition services, including the following:

   (a) Beginning at age 14, and updated annually, a statement of the transition service needs of the student under the applicable components of the student's IEP that focuses on the student's courses of study (such as participation in a vocational education program).

   (b) Beginning at age 16 (or younger, if determined appropriate by the IEP team), a statement of needed transition services for the student, including, when appropriate, a statement of the interagency responsibilities or any needed linkages.

The initial evaluation [see (a) above] is conducted by an IEP team, which is composed of the following people (Individuals with Disabilities Education Act Amendments, 1997, section d.1.B.):

1. The parents of the student with a disability.

2. At least one regular education teacher of the student (if the student is, or may be, participating in the regular education environment).

3. At least one special education teacher, or where appropriate, at least one special education provider for the student.

4. A representative of the local educational agency who is qualified to provide, or supervise the provision of, specially designed instruction to meet the unique needs of children with disabilities.

5. An individual who can interpret the instructional implications of evaluation results, who may be a member of the team as described in 2 through 6.

6. At the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the student, including related services personnel as appropriate (e.g., VR counselor).

7. Whenever appropriate, the student with a disability.

The interests of the IEP team, with respect to transition planning, converge with the interests of the VR system, and provide a mechanism *where the two systems can work together effectively*! Each IEP is developed by the IEP team, which must consider the following issues:

1. The strengths of the student and the concerns of the individual and his or her parents for enhancing the education of their child.

2. The results of the initial evaluation or most recent evaluation of the student.

3. Strategies, when appropriate, including positive behavioral interventions and supports to address that behavior, in the case of a student whose behavior impedes his or her learning or that of others.

4. All resources available in the area from individuals, team members, and relevant agencies.

The multidisciplinary IEP team, including a VR counselor, is very similar to the kind of diagnostic team mentioned earlier. In fact, it is recommended that there be considerable overlap between the two, if they are not completely the same.

IPE: Special considerations

An individualized plan for employment (IPE), formerly an individualized written rehabilitation plan (IWRP), contains documents in the client's file that are the official record of the intake, application, assessment, eligibility for services, and plan of services for the client. Of these, references to the IPE usually refer to the plan of services for the client, which must include the following items:

1. A specific vocational goal, such as auto mechanic, bookkeeper, counselor, nurse, artist, or janitor.

2. Types of services, names of providers, and duration of service for each one. Each service necessary to correct, ameliorate, or circumvent functional limitations and to help obtain the job goal should be specifically identified. The planned beginning and ending dates for each service must also be stated. Vital services needed to achieve the vocational goal should be listed even if VR will not be paying for it or arranging it.

3. Criteria for measuring and documenting progress, including the client's responsibilities (intermediate objectives), should be established. It is important to recognize that the client is not merely a passive recipient of services, but is an active participant in the process of vocational rehabilitation. It is also a good idea to specify criteria for recognizing when a service has been completed or is no longer needed.

4. The individual or organization responsible for providing or paying for each service. The payer can be VR, another agency, or even the client, if he or she can afford it.

VR services can provide selected vocationally and educationally related services to youths over 16 years of age who are currently enrolled in school. To provide these services, a written cooperative agreement between the local education agency (LEA) and VR is necessary. This cooperative agreement must state specifically which services the school is unable to provide that may be required in the student's IEP, that are within the scope of VR services, and are not available as a similar benefit from a third resource [DES 4-3-03.C, 1982].

The IPE should pay special attention to two functional limitations typical of persons with FAS/FARC: (a) difficulty with interpersonal relationships and social skills (Section, Functional Limitations, paragraph 04) and (b) learning style differences, including a lack of understanding of cause and effect (Section, Functional Limitations, paragraph 08). Dealing effectively with these functional limitations requires a structured, organized, slower paced environment (Appendix C). Integration into a new work environment typically requires communication skills, facility with social interaction, and impulsivity control--which are often a source of difficulty for people who have FAS/ARND. For these reasons, social skills training and job coaching are frequently needed (Appendix C).

Exercise: Case Study #3: Matthew B.

Matthew B. is a 20-year-old male of Native descent who was born to a 16-year-old girl who consumed at least 6–10 cans of beer a day throughout much of her pregnancy. This had been her pattern of alcohol consumption since the age of 9. Matthew's mother, due to her age, emotional problems, and heavy alcohol use, was unable to care for him. She had left him at home alone and unattended for several days. The neighbors became worried about the baby and the Child Protective Services agency was called.

Matthew was placed in foster care at the age of 17 months. The neighbor, a young married Caucasian woman who made the initial call to CPS, took Matthew as a foster child 1 month later. His birth mother gave her consent for this placement, and voluntarily relinquished her maternal rights 6 months later. Matthew was adopted by his foster family in an open adoption. He has had sporadic contact with his biological mother up to the present. His rate of visitation depends on her level of alcohol use and Matthew's ability to handle his birth mother's erratic behavior.

Matthew's family originally lived in a small rural community. His adoptive parents divorced when he was 5. He, his mother, and her biological daughter, an infant of 2 months, moved to a large urban center. The mother remarried 2 years later and the family has remained in the urban area, indeed in the same home, for the past 13 years.

Matthew, from the time of his birth, showed developmental delays. He was longer than normal at birth but markedly underweight. His biological father was later determined to be 6' 5" tall and his birth mother was 5' 1". Matthew, throughout his developmental history, continued to be above average for height but below the 5th percentile for weight. He showed significant developmental delays in walking, talking,

and toilet training. Much of this was thought, originally, to be related to the repeated physical neglect he experienced in his birth home.

Matthew was placed by his adoptive mother in preschool at the age of 3. While his home environment was calm, well structured, and predictable, the preschool he had been placed in did not have these qualities. Matthew was unable to function in this environment. Because of difficulties related to his behavior, it was necessary for him to remain at home with his mother until age 6 when he began kindergarten.

Upon entering first grade, Matthew's challenging behaviors and various successful interventions (scheduling, specific structure, adapting the classroom) were shared with the administrative and teaching staff at the elementary school he was to attend. A psychological and adaptive behavior assessment was done. As a result of this evaluation, Matthew was placed in a self-contained special education class. He was maintained in self-contained classes until the seventh grade when he was mainstreamed into regular classes with the exception of math and language arts. Despite remediation attempts in these subjects, Matthew had great difficulties with abstract concepts and tasks. He is, however, musical and artistic and has good visual spatial skills.

Matthew's social skills have been poor and he has had psychiatric and behavioral difficulties as well. The latter have included impulsivity, psychotic episodes, perseverative behavior, anger outbursts, and severe social withdrawal. He was diagnosed as having Asberger's disorder (DSM IV code 299.80), and placed on a series of medications including Cylert, Ritalin, and Imipramine in conjunction with an antipsychotic agent.

Matthew graduated from high school at the age of 18. He was placed in a Department of VR program and trained in computer data entry and processing. After successfully completing his training, he was placed in a small accounting firm where it is his job to input a variety of data. His data entry program is such that he receives automated quality control feedback on a continuous basis.

He works 5 hours per day or more if he is able. His supervisor works in the same area and allows Matthew up to 10 minutes per hour of break time. Matthew has been in this placement for nearly 2 years.

He is currently living in an adult DD home with four other young men. He is still on his medication and still showing serious signs of social withdrawal. He has overnight visitation with his family twice a month.

Matthew's IQ, academic achievement, and adaptive behavior scores are listed below. (Testing at age 19.)

Wechsler Adult Intelligence Scale-III (WAIS-III)	
Subscale	Score
VIQ	62
PIQ	103
FSIQ	68

Wide Range Achievement Test-3 (WRAT-3)		
	SS	GE
Reading	89	HS
Spelling	74	8th
Arithmetic	63	5th

Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
Communication	92	12.5 years
Daily Living Skills	103	14.0 years
Socialization Skills	58	6.8 years
Adaptive Behavior Composite	84	11.2 years
Maladaptive Level	*Significant*	

Questions:

1. What are the factors presented that would suggest Matthew does or does not have FAS/FARC?
2. What are Matthew's areas of skills or strengths?
3. What disabilities should Matthew be tested for?
4. What long-term interventions might be considered to aid Matthew?
5. What, if any, further assessments should be done with Matthew?
6. What goals for employment should be considered?

V. IMPLEMENTING AN INDIVIDUALIZED PLAN

The purpose of the procedures outlined in this manual is to help the client and his or her providers to have a successful outcome and to achieve the client's full potential. This is a goal that all parties, especially the client, must endorse and support. As the assessment is completed and the individualized plan is written, the "whole" of the client and his or her life should remain the central focus throughout the project.

Mental health issues, poor social skills, impulsivity, poor judgment, a lack of abstracting abilities, and poor discrimination and generalization abilities are common concerns for people with FAS and fetal alcohol-related conditions. These factors often have a profound effect on the client's ability to acquire and retain gainful employment or have a successful educational experience. However, they can meaningfully participate in person-centered planning if members of the team understand how to work with people who have FAS. A good assessment, along with a well-written individualized plan, provides steps toward change for the client. When these steps have been taken, the challenge then becomes one of implementation.

Identifying Resources

Finding the appropriate job for any client is only one piece of the employment puzzle for people with FAS/FARC. Listed below are other supportive services that need to be in place to help the client build toward success:

1. A case manager to oversee program implementation.
2. A safe, stable residential placement.
3. Transportation.
4. Education of the employer about FAS and the type of teaching, structure, supervision, and monitoring that would be helpful.
5. A mentor in the work environment to help with the items in step 4.

6. A money-manager to monitor and protect any of the client's income.

Team Building

Clients with FAS have multiple needs. A case manager should be assigned and the client support team should meet as often as needed but no less than quarterly. These meetings could include, as appropriate, the case manager, mental health therapist, employer or supervisor, social worker, caregiver, client, VR counselor, and job developer or job coach.

The team meeting can be used to assess the appropriateness of the program, to identify concerns early on, to make adjustment as needed, and to ensure that the client is included, as much as reasonable, in program decision and design. Collaboration and communication are the key factors in building a successful team and increasing the chances of a successful outcome for the client.

Strategies for Maximizing Success

People with FAS and related conditions often benefit from repetition, a very structured environment, and from visual cueing rather than verbal cueing. In this section, some specific suggestions will be highlighted to illustrate these general principles.

- Use well defined areas. Things are put away in a certain place, perhaps with a masking tape border to outline the area.
- Remove extraneous materials. Limit the number of objects and displays in room at one time. Use visual displays, then remove them. Keep work areas cleared off, except for materials in use.
- Keep worksheets uncluttered, with lots of white space on the page. Use fewer pictures or problems so the page is not so busy or filled with data.
- Use pictorial cues as reminders of routines. Use pictorial signs for subject areas, special room areas and location signs such as parking area.
- Use Brain Maps. Draw a one-page visualization of a lesson. It gets the student or client thinking in terms of graphic relationships instead of verbal connections. In the process of creating visuals for their memory map, they are drawing pictures in

their brain that will last much longer than words.

- Adapt tasks and materials in terms of frustration tolerance. Shorten the time, number of examples or trials. Simplify material and concepts. When the task is shortened, the student or client is rewarded with a sense of completion.

- Give direct instruction in thinking skills. Ask the client- How'd you figure that out? What did you do first...? Instructor can model this by thinking out loud so that the student or client hears the instructor's thinking strategies.

- Use the "broken record" technique by repeating the same words over and over again to strengthen the memory. For example, at the end of each session, "What is the last thing we always do?" Reply: "Turn off the lights." People with FAS and related conditions often need more repetitions to learn something than other people do.

- Anticipate- know danger signs and situations. Build relaxation time into the program. For example, when a client who has FAS starts tapping his/her feet and drumming his/her fingers, she needs to discharge that energy or she can erupt into aggressive behavior. Let her "take a little break now" and speed walk around the building until he/she feels calmed down.

- Teach appropriate ways to respond to overwhelming stimuli. The client can move to another part of the room, ask others to be quiet, or ask permission to leave the group temporarily.

- Encouragement works better than praise. Say, "I know you can do that... You did that part right! Let's try it again."

- Chunk work. Break the work into small pieces. This reduces anxiety, and decreases the tendency to think "I'll never get this all done."

- Repeat and restructure continually. Express it different ways, show them through different modalities, including visual, kinesthetic (body movement) and haptic (touch).

- Teach them to ask for repetition of instructions or material in a form other than the one you just used. (Would you write that down for me please? Can we make a diagram?)

- Stop at key points in order to determine the client's understanding.

- Focus on generalization of skills and behaviors. Generalization is the process of learning a behavior or forming a belief about a specific situation or concept, which

is then applicable to a whole class or ideas, people and/or events. When a lesson is taught, don't assume that they will automatically know how to generalize the information to new situations. They often will not know how to do that. We have to point out other situations and get them to actively think about it. When else would you do this? Do you think it would work here? How is that situation similar to this one?

- It also helps to link new learning to prior experience. Fitting information together is the key to successful generalization of knowledge.

- Teach social skills, such as:

  A. How to negotiate to get what you want.

  B. How to disagree with someone else in an appropriate way.

  C. How to show someone you like them (appropriately).

  D. How to accept criticism or negative feedback.

  E. How to ask for something in a way that will increase the odds you will get it.

  F. How to get someone's attention in a positive way.

  G. How to give and take a compliment.

  H. How to start a conversation.

  I. How to say no to peer pressure.

  J. How to act when riding public transportation.

  K. What to do when you feel scared.

<u>Facilitating employment success</u>

- Ask professionals to call and confirm appointments in a timely fashion. Difficulty with keeping appointments seems to be a direct manifestation of FAS (Devries & Waller, 1999).

- Position the client directly across from the employer when speaking, looking directly at the speaker so that eye contact can be maintained. If the client comes from a traditional American Indian or Alaska Native background, make sure they understand that maintaining eye contact with a non-Indian employer is expected, and not a sign of disrespect.

- Alert the client or student in advance of activity change: people with FAS or

related conditions often have difficulty with transitions. "We have ten more minutes before lunch. . . We have five more minutes!. . . You should be finishing up."

- Train the student or client to get ready for work the night before, getting clothes laid out, get lunch money ready, and so on.

- Use calendars and assignment books. Teach them how to use them and review their use of them every day for the first two weeks, then once a week.

- Assign short tasks and give explicit, concrete, and carefully defined directions. Instructions or directions like "Go to the Fork in the road. . . Does that ring a bell? Give her the brush off... Let's talk turkey! Why don't you just throw in the towel!" are very confusing, because people with FAS and related conditions often translate language in a very concrete fashion.

- Avoid giving multi-part verbal instructions. People with FAS and related conditions often find it difficult to remember complicated verbal instructions.

- Increase the client's attention by shutting out all unnecessary auditory stimulation that they don't need to hear. Use earphones with no auditory stimuli to screen out extraneous noise.

- Use a "study carrel" type of office space to shut out visual stimulation, reducing distractions.

- Ask the client to repeat back directions in their own words, paraphrasing what was said so that you are sure that the information was processed.

- After the first several items are completed, check back to make sure they understand the next steps of the task, have not gotten distracted, and have not forgotten how to do the next task.

- People with FAS or related conditions often have significant difficulty dealing with public transportation. Be alert for problems in this area, and help the client or student learn how to deal with them.

Finally, people with FAS or related conditions often benefit significantly from an advocate. The advocate can be a family member, a job coach, or a friend. One of the important advocacy roles is to educate the employer about core disability issues such as those enumerated above. Another important role is to determine when problems are occurring, so that troubleshooting and remediation can prevent termination of

employment.

Troubleshooting

One of the most common concerns and problems is setting unreasonable goals and expectations for clients with FAS/FARC. Under favorable circumstances, these clients often have a chatty and gregarious manner, appearing to have not only adequate or above-average verbal skills but also a full comprehension of what is expected of them. The gap between appearance and reality is a common source of frustration and problems between the employer and client with FAS/FARC.

To illustrate how unrealistic expectations can widen the gap between appearance and reality, Dan Dubovsky (1998) has suggested that instead of behavior that is normal, people affected by prenatal alcohol exposure under unfavorable circumstances often appear NURMU, an acronym for Non-compliant, Uncooperative, Resistant, Manipulative, and Unmotivated. His point is that these labels assume a knowledge of the motives of people with FAS or FARC that does not take into account the difficulties with communication and social skills common to this population. If someone doesn't follow directions that others seem to understand, we often jump to the conclusion that they would not do it, rather than consider the possibility that they can not do it because they don't understand or can not remember all the steps. Remembering a list of directions, for example, is something people with FAS often find difficult. In other words, each of these five labels may misrepresent the actual cognitions and behavior motives of the client.

Therefore, when troubleshooting, it is important to look not only at the *person*, but also at the *environment*. For example, a person who uses a wheelchair in a city where there are no curb cuts, and where the entrance to public places requires use of stairways, is said to live in a disabling environment. As a result of the Americans with Disabilities Act, public accommodations must be accessible. Similarly, a person with organic brain dysfunction such as FAS/FARC may find certain environments disabling. Specifically, many persons with FAS/FARC are easily distractible. An environment

that many people would find stimulating is instead experienced as quite distracting. A person who has a difficult time completing tasks in a noisy common work area may have far less difficulty completing the same tasks in a quieter environment where there are fewer audio-visual distractions.

The case manager or a job coach can play a crucial role in reducing, if not eliminating, the problems that often result from unrealistic expectations on the part of all involved. For example, giving directions one step at a time is usually more effective than giving complex instructions. Many clients with FAS/FARC have difficulty telling time by a watch with a dial. Having a digital clock, which is easier to read, with a work schedule posted nearby is often useful in keeping the client on task. It is also helpful to convene the interdisciplinary team frequently for accomplishment audits, which help stakeholders keep in touch with their successes and build a sense of pride in their work together.

A job coach can often make a significant difference in the long-term outcome of a placement. A job coach trained to work with persons who have FAS/FARC can be a tremendous asset not only in initial job adjustments, but in the long-term outcome. The sudden withdrawal of a job coach may precipitate readjustment problems. It is often better to wean the client from dependency on the job coach gradually.

A pre-employment interview outlining the client's skills and providing information such as the above to the potential employer may reduce unrealistic expectations and promote a more viable work environment. Such an interview will provide both the client and the employer a chance to discuss concerns and establish positive structure from the outset.

Streissguth and Barr (1998) focused their study on the Native Americans in the sample studied by Streissguth, et al. (1996), and both analyzed the employment experiences of the adults in their samples who had FAS or related conditions. A comparison of their results showed that "lying" on the job was almost twice as frequent among the Native Americans (Streissguth & Barr, 1998), as it was among persons with FAS/FARC in the general population, including Native Americans (Streissguth et al.,

1996). Lying is a problematic concept with many persons who have FAS or FARC, who often have difficulty with abstractions. These percentages become more understandable when we add the possibility of cross-cultural misunderstandings. If an employee who has a cognitive impairment as a result of prenatal exposure to alcohol says something that is not "true," it may be important to find out whether there is intent to deceive, rather than something else. The employer might jump to the conclusion that the employee is dishonest and not trustworthy, and fire the employee. However, a sensitive interview might disclose an entirely different situation, with a different solution. Here is where the client's interdisciplinary team can find out what really happened, and work out a solution that the employer can live with.

Exercise: Case Study #4: Treena S.

Treena S. is a 35-year-old female of Native descent who resides with her biological mother, two of her four older siblings, and five nieces and nephews in a small reservation community. Her father died of cancer at the age of 43 when Treena was 3 years old; her mother has not remarried. Treena's mother, at age 75, is still drinking. She acknowledges having several binges during her early pregnancy. These binges consisted of up to 18 drinks of whiskey over a 3–4 hour period. She was hospitalized multiple times for alcohol poisoning. She denies drinking after the fourth month of her pregnancy, although the accuracy of this report is not known.

Treena is quite growth deficient, being below the 5th percentile for height, weight, and head circumference. She was unable to complete school and has been on Social Security Disability since the age of 18. She has limited verbal and cognitive skills and has deficits in her memory and abstracting abilities. However, her visual skills are good and she has considerable artistic and musical ability. She is also very good with her nieces and nephews.

Treena has not had a significant history of impulsivity or legal concerns but she has been sexually exploited many times, the result being two pregnancies. Both of these pregnancies ended in miscarriages and Treena is now on Depo-Provera for birth control. She began drinking in her early teens and drinks in a binge pattern along with her mother and one of her older siblings. She has been through the tribal alcohol program six times without successful abstinence.

The two older siblings, a brother and sister, who reside with Treena and her mother, both work off the reservation. Neither of them is presently married and both are abstinent from alcohol. Treena's mother is recently showing signs of Alzheimer's

and chronic liver disease secondary to her long-term alcoholism. Several times in the past 3 months, Treena's mother has wandered away from the family home and been brought back by other relatives and neighbors living in the immediate vicinity.

Although Treena's brother and sister would like to continue caring for her, they feel that they cannot provide a home for both her and their ailing mother. The oldest two siblings are living off the reservation and the one who takes Treena on the binges is not considered a viable option for Treena's placement. After the last incident where Mrs. S. wandered away from home, Treena's brother and sister consulted a physician and social worker about what options were available in their community.

One of the referrals they received was for a VR program for Treena, one specifically intended to make use of her good artistic and visual spatial skills. An appointment was made and her assessment scores are listed below. Shortly after the referral was made, Treena's mother's health deteriorated to the point where she was placed in a nursing home. (Testing at age 35.)

Wechsler Adult Intelligence Scale-III (WAIS-III)	
Subscale	Score
VIQ	62
PIQ	69
FSIQ	66

Wide Range Achievement Test-3 (WRAT-3)		
	SS	GE
Reading	66	3
Spelling	50	>3
Arithmetic	>40	>3

Vineland Adaptive Behavior Scales (VABS)		
	SS	AE
Communication	55	7.5 years
Daily Living Skills	63	8.1 years
Socialization Skills	50	5.5 years
Adaptive Behavior Composite	56	7.0 years
Maladaptive Behavior	*Not Significant*	

Questions:

1. Is it likely that Treena has fetal alcohol syndrome? On what are you basing your answer?
2. What disabilities should Treena be assessed for? Is mental retardation likely?
3. Is Treena a more likely candidate for VR or independent living services? If so, in what types of settings and in what types of programs?
4. What are some of the significant secondary disabilities that may impact her gainful employment or independent living?
5. What are the paramount concerns in Treena's life, beyond employment and independent living? What might some of the recommendations be to address these issues?
6. What is Treena's prognosis?

VI. EVALUATION

The final portion of the process for successfully integrating the client with a disability back into the school or employment world is an ongoing process of reevaluating the individualized plan. Program evaluation should include the following items:

1. Timely completion of special programs.
2. Achievement of goals.
3. Client's improved functioning in the areas assessed by the instruments discussed in this manual.
4. Client's satisfaction with his or her placement.

The interdisciplinary team should meet as needed, once a quarter at the start of the program, and less as the program progresses and supports are established. The client should be included in these meetings as often as possible. Changes to the program should be ongoing to ensure that the client is able to achieve the desired outcome, and is satisfied with the results. If this is not occurring, the team should work together to identify obstacles and to make plans for overcoming these obstacles.

Exercise #5

Review the case of Matthew (Case 3). What criteria would you use to evaluate his placement? Is this placement meeting his short-term goals but not his long-term goals? Consider the following options:

1. His case can be closed and there is no need for any further support.
2. His case can be closed if certain ongoing supports are assured (identify those supports).
3. His individualized plan for employment (IPE) should be reviewed with Matthew to determine if this placement is meeting his long-term as well as short-term goals.

In summary, this manual emphasizes person-centered planning for American Indians who have FAS or related conditions. This approach involves the use of multidisciplinary teams in diagnosis (Clarren & Astley, 1997) as well as in educational and employment planning, based on the IEP model mandated by the Individuals with Disabilities Education Act (IDEA), as amended in 1997. We feel that this approach works across disciplines and through time to help each client achieve his or her maximum potential.

No human is worth any less than this!!!

REFERENCES

Aase, J. M. (1981). The fetal alcohol syndrome in American Indians: A high risk group. *Neurobehavioral Toxicology and Teratology, 3* (2), 153–156.

Astley, S. J., & Clarren, S. K. (1997). *Diagnostic guide for fetal alcohol syndrome and related conditions: The 4-digit diagnostic code*. Seattle, WA: University of Washington.

Berg, S., Kinsey, K., Lutke, J., & Wheway, D. (1995). *FASNET assessment tool for use with adults (19 years of age and up)*. Surrey, B.C.: FAS/E Support Network.

Boufford, J. I. (1997). *Healthy People 2000: Progress review. People with disabilities.* Washington, DC: Department of Health and Human Services.

Church, M. W., & Kaltenbach, J. A. (1997). Hearing, speech, language, and vestibular disorders in the fetal alcohol syndrome: A literature review. *Alcoholism: Clinical and Experimental Research, 21* (3), 495–512.

Church, M. W., Eldis, F., Blakley, B. W., & Bawle, E. V. (1997). Hearing, language, speech, vestibular, and dentofacial disorders in fetal alcohol syndrome. *Alcoholism: Clinical and Experimental Research, 21 (2)*, 227–237.

Clarren, S., & Astley, S. (1997). Development of the FAS diagnostic and prevention network in Washington state. In A. P. Streissguth & J. Kanter (Eds.), *The challenge of fetal alcohol syndrome* (pp. 40–51). Seattle: University of Washington Press.

Colberg, K. (1997). Fetal alcohol syndrome: Prevalence, risk factors, prevention. *State of Alaska Epidemiology Bulletin, 1* (2).

Conry, J. (1990). Neuropsychological deficits in fetal alcohol syndrome and fetal alcohol effects. *Alcoholism: Clinical and Experimental Research, 14*, 650–655.

DeVries, J. & Waller, A. (1999). *FAS/E Interventions that Work for Adults*. F.A.S. Times, Special Edition 1999. Lynnwood, WA: Family Resource Institute.

Division of Developmental Disabilities. (1993). *Policy and Procedures Manual: Plan Development* (Rev. ed.). Phoenix, AZ: Department of Economic Security.

Dubovsky, D. (Presenter). (1998). *Long-term care issues for adolescents and adults with FAS/FAE* [audio teleconference, March 19, 1998]. Audiotape available from Family Empowerment Network, 610 Langdon Street, Room 521, Madison, WI 53703.

Gessner, B., Bischoff, H., Perham-Hester, K., Chandler, B., & Middaugh, J. (1998). Educational attainment of children with fetal alcohol syndrome. *State of Alaska Epidemiology Bulletin, 2* (3), 1–14.

Individuals with Disabilities Education Act Amendments. (1997). P.L. 105-17.

Hill, B. K. (1998). Adaptive and maladaptive behavior scales. Internet: http://www.isd.net/bhill/compare.htm.

Jones, K. L., & Smith, D. W. (1973, November 3). Recognition of the fetal alcohol syndrome in early infancy. *Lancet, 2*, 999–1001.

Little, R. E., Asker, R. L., Sampson, P. D., & Renwick, J. H. (1986) Fetal growth and moderate drinking in early pregnancy. *American Journal of Epidemiology, 123*, 270–278.

Marge, M. (1988). Health promotion for persons with disabilities: Moving beyond rehabilitation. *American Journal of Health Promotion, 2*, 29–44.

Marone, J., Hoff, D., & Helm, D. T. (1997). Person-centered planning for the millennium: We're old enough to remember when PCP was just a drug. *Journal of Vocational Rehabilitation, 8*, 285–297.

National Center for Health Statistics (1997). *Healthy People 2000 Review, 1997*. Hyattsville, MD: Public Health Service.

SIB-R User's Group. (1998). Home page, http://www.isd.net/bhill/sibr.htm.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984).*Vineland Adaptive Behavior Scales*. Circle Pines, MN: American Guidance Service.

Stratton, K., Howe, C., & Battaglia, F. (Eds.). (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment*. Institute of Medicine, Washington, DC: National Academy Press.

Streissguth, A. (1997). *Fetal Alcohol Syndrome: A Guide for Families and Communities*. Baltimore: Paul H. Brookes Pub. Co.

Streissguth, A. P., & Barr, H. M. (1998). *The school and employment experience of Native American adolescents and adults with FAS/ARND*. Technical Report No. 98-05. Seattle, WA: Fetal Alcohol and Drug Unit, University of Washington School of Medicine.

Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final Report*. Seattle, WA: Fetal Alcohol and Drug Unit, University of Washington School of Medicine.

Streissguth, A. P., Bookstein, F., Barr, H. M., Press, S., & Sampson, P. (1998). A fetal alcohol behavior scale. *Alcoholism: Clinical and Experimental Research, 22* (2), 325–333.

Streissguth, A. P., Clarren, S. K., & Jones, K. L. (1985). Natural history of the fetal alcohol syndrome: A 10-year follow-up of eleven patients. *Lancet, 13*, 85–91.

Streissguth, A. P., LaDue, R., & Randels, S. (1988). A manual on adolescents and adults with fetal alcohol syndrome with special reference to American Indians (Rev. ed.). Seattle, WA: University of Washington.

Uecker, A., & Nadell, L. (1996). Spatial locations gone awry: Object and spatial memory deficits in children with fetal alcohol syndrome. *Neuropsychologia, 34*, 209–233.

Wegmann, M., Colfax, L., Gray, M., & Reed, B. (1998). Assessment & resource guide for FAS/FAE (Rev. ed.). Port Angeles, WA: Pen Print.

Appendix A:

FETAL ALCOHOL EXPOSURE RISK ASSESSMENT FOR ADOLESCENTS AND ADULTS

FETAL ALCOHOL EXPOSURE RISK ASSESSMENT FOR ADOLESCENTS AND ADULTS

Name:_____ Date of Exam:_____

Age:_____ Date Of Birth:_____ Gender: M F Race/Ethnicity:_____

Form Completed By:_____ Phone #:_____

Sources of Data (please check all that apply)

Record Review _____ Date_____ Interview of Client _____ Date_____

Interview of Caretaker _____ Date_____ Interview of Parent _____ Date_____

(Instructions: Fill out information about the risk factors on the left side of the table and then use that data to summarize the risk of FAS on the right.)

I. Maternal Alcohol Use History During Pregnancy

Maternal History of Alcoholism: Confirmed:_____ Suspected:_____

Fetal Exposures to Alcohol: Confirmed:_____ Suspected:_____

Binge drinking (4 or more drinks per occasion)

	☐ none	☐ 1-2x	☐ 3-4x	☐ >4x
Frequency	☐ none	☐ 1-2days/wk	☐ 3-4days/wk	☐ >4days/wk
Quantity	☐ none	☐ 1 drink	☐ 2-3 drinks	☐ 4 or more
Alcohol use by trimester		☐ first	☐ second	☐ third

Summary of Alcohol Use During Pregnancy

☐ 1. No risk
☐ 2. Information not available; Not sure
☐ 3. Low risk use
☐ 4. High-risk use

II. Growth Pattern at age:_____ (Use preschool data if possible)

Weight _____kg **Standard Score:** _____

Height _____inches **Standard Score:** _____

Mother's height _____inches Father's height _____inches

Summary of Growth

☐ 1. Normal growth
☐ 2. Not Sure
☐ 3. Probable growth retardation
☐ 4. Definite retardation

III. Facial Phenotype

Palpebral fissure length _____ _____%

Inner Canthal distance _____ _____%

Epicanthal folds	☐ present	☐ not sure	☐ not present
Upper lip	☐ very thin	☐ in-between	☐ normal
Philtrum	☐ flat	☐ elongated	☐ normal

Photograph Y N Date taken_____ Age_____

Summary of Facial Malformation

☐ 1. Normal exam
☐ 2. Not sure
☐ 3. Abnormality probable
☐ 4. Abnormality certain

IV. Neurodevelopmental Disorders

Head circumference less than 21 inches (males) or 20.5 inches (females)	☐ present	☐ not sure	☐ not present
Mental retardation	☐ present	☐ not sure	☐ not present
Borderline Intellectual functioning	☐ present	☐ not sure	☐ not present
Learning disability	☐ present	☐ not sure	☐ not present
Attentional problems	☐ present	☐ not sure	☐ not present
Receptive/Expressive Language disorder	☐ present	☐ not sure	☐ not present
Depression	☐ present	☐ not sure	☐ not present
Conduct disorder	☐ present	☐ not sure	☐ not present
Oppositional Defiant disorder	☐ present	☐ not sure	☐ not present

Summary of Neurodevelopmental Disorders (see over)

☐ 1. Normal exam
☐ 2. Not sure
☐ 3. Abnormality probable
☐ 4. Abnormality certain

II. Description of Growth Pattern

Growth pattern is "abnormal" if:

- person was in the lowest 5 percentile for height **or** weight in preschool
- person was in the lowest 10 percentile for height **and** weight in preschool
- person is unusually small for his/her age, gender, and family.

III. Facial Phenotype

- Philtrum smoothness and lip thinness are best assessed from a frontal face photograph taken between the ages of 2 and 12, with a neutral facial expression.
- In the presence of epicanthal folds, the palpebral fissure length may be difficult to ascertain.

IV. Neurodevelopmental disorders

Neurodevelopmental disorders can be considered "abnormal" if

- head circumference is less than 21 inches (males)/ 20.5 inches (females), or
- mental retardation is present, or
- any of the listed disorders are considered "severe," or
- there is more than one listed disorder.

V. Other Physical Abnormalities

There may also be some physical abnormalities associated with fetal alcohol exposure that might indicate a diagnosis of Alcohol-Related Birth Defects (ARBD). These include:

- **Ophthalmologic** (In addition to small palpebral fissures and a larger Inner Canthal distance) – Corneal or lens problems; Ptosis; Strabismus; Retinal abnormalities (optic disc abnormalities)

- **Otologic** – Conductive hearing loss; Sensorineural hearing loss; Posterior rotation of external ear; abnormal frequency or duration of otitis media; abnormalities of the Eustachian tubes

When combined with positive indicators of the four diagnostic categories summarized below, such physical abnormalities provide further support for the need to refer for evaluation of FAS and related conditions.

Summary *(please summarize data from the preceding page)*

I.	At-risk maternal alcohol use	☐ 4. Certain	☐ 3. Probable	☐ 2. Not sure	☐ 1. none
II.	Growth retardation	☐ 4. Certain	☐ 3. Probable	☐ 2. Not sure	☐ 1. none
III.	Facial abnormalities	☐ 4. Certain	☐ 3. Probable	☐ 2. Not sure	☐ 1. none
IV.	Neurodevelopmental disorders	☐ 4. Certain	☐ 3. Probable	☐ 2. Not sure	☐ 1. none

If I, II, III, & IV are rated 3 or 4 (certain or probable), this person is at risk for Fetal Alcohol Syndrome and should be referred for evaluation of FAS (and to exclude other causes).
If IV is rated 3 or 4 (certain or probable), and I is rated 2 or more, this person may be at risk for alcohol-related neurodevelopmental disorder (ARND) and should also be referred for evaluation.
Proper diagnosis and disability assessment greatly enhances opportunities for successful outcomes. With both, outcomes become much more manageable. For evaluation of FAS and related conditions in your

area, please contact: _____

Appendix B:

PSYCHOSOCIAL NEEDS ASSOCIATED WITH FETAL ALCOHOL SYNDROME

PSYCHOSOCIAL NEEDS ASSOCIATED WITH FETAL ALCOHOL SYNDROME:
PRACTICAL GUIDELINES FOR PARENTS AND CARETAKERS

Robin A. LaDue, Ph.D.
Fetal Alcohol & Drug Unit
University of Washington, School of Medicine, GG-20
Seattle, Washington 98195

ADOLESCENCE
AGES 12 - 17 YEARS

Problems and Concerns:

- Academic ceiling is often reached; usually 4th grade for Reading, 3rd grade for Spelling and Arithmetic
- Increasing social difficulties and isolation
- Low motivation
- Egocentric, difficulty comprehending and/or responding to other's feelings, needs, and desires
- Lying, stealing, passivity in responding to requests
- Faulty logic

Problems and Concerns:

- Impulsive, aggressive, unpredictable, & violent behavior
- Involvement in vandalism, other criminal activity
- Pregnancy/fathering a child
- Loss of residential placement
- Low self-esteem and mental health issues
  - Depression
  - Suicidal ideation and attempts
  - Substance abuse
  - Sexual/emotional abuse and trauma

Recommendations:

- Change focus from academic skills to vocational and daily living skills
- Continued structuring and monitoring of leisure time and activities
- Involvement in structured social and sport group activities
- Anticipation of transition/crises situations along with appropriate planning and early interventions

Recommendations:

- Help the patient to make healthy choices and to build on his or her existing skills
- Education of parents, caretakers, and patients regarding sexual development, birth control options, and protection against sexually transmitted diseases (STDs)
- Education of parents, caretakers, and patients to help protect against sexual exploitation
- Implement planning for future residential placement, financial needs, and vocational/educational training

Recommendations:

- Case manager role expands to include acting as a liaison between patient, family, schools, vocational programs, health care providers, and court services, if necessary
- Continued listing of daily chores with increasing responsibility
- Respite care for families
- Caretakers support group

PSYCHOSOCIAL NEEDS ASSOCIATED WITH FETAL ALCOHOL SYNDROME:
PRACTICAL GUIDELINES FOR PARENTS AND CARETAKERS

Robin A. LaDue, Ph.D.
Fetal Alcohol & Drug Unit
University of Washington, School of Medicine, GG-20
Seattle, Washington 98195

ADULTHOOD
AGES 18 + YEARS

Problems and Concerns:

- Increased expectations of the patient by others
- Increased dissatisfaction towards the patient by others
- Unpredictable and impulsive behavior
- Aggressive and violent behavior
- Depression/Suicidal ideation and attempts
- Poor comprehension of social expectations

Problems and Concerns:

- Withdrawal and social isolation
- Social/sexual/financial exploitation
- Economic support and protection
- Job training and placement
- Medical care
- Birth control/pregnancy/fathering a child
- Child care
- Legal issues, incarceration

Recommendations:

- Guardianship for funds
- Subsidized residential placements, including special moneys for biologic & adoptive parents to help defray costs for special needs
- "Homebuilders" support to help the patient live as independently as possible and to help in teaching parenting skills if the patient has children
- Specialized vocational training and/or job placements
- Medical coupons and care
- Case manager to help patients and families access services
    - Drug and alcohol treatment for patient, if needed
    - To act as liaison with court and other legal concerns, if necessary
- Patient advocates to ensure the recommendations are acknowledged and implemented

Recommendations:

- Acknowledgment of the patient's limitations, strengths and skills
- Acceptance of the patient's "world"

Appendix C:

VOCATIONAL DEVELOPMENT FOR INDIVIDUALS WITH FAS/FAE

Vocational Development for Individuals with Fetal Alcohol Syndrome
or Fetal Alcohol Effects: Part I

Georgiana Wilton, MA

Fetal Alcohol Syndrome (FAS) is the most common known cause of mental retardation (National Institute on Alcohol Abuse and Alcoholism, (NIAAA) 1987), and is the only one that is truly preventable. Since its recognition in 1973, thousands of articles have been written on the subject. Although FAS has received attention by several leading researchers in this country, it is still a relatively young diagnosis—having only been recognized for the last 25 years. Only one major long-term study has been conducted to examine the types and magnitude of secondary disabilities that are associated with FAS and Fetal Alcohol Effects (FAE). Therefore, information regarding long-term expectations, including vocational implications for adults, is severely lacking.

Fetal Alcohol Syndrome is a pattern of birth defects seen in the offspring of some women who consumed high levels of alcohol during their pregnancy. It is important to note that not all children who are exposed prenatally to alcohol will have effects. The Jones and coworkers study (as cited in Aase, 1994) defined three major categories of abnormality in children with FAS: slow growth both before and after birth, involving height, weight, and head circumference; deficient intellectual and social performance and muscular coordination; a consistent pattern of minor structural anomalies of the face, together with more variable involvement of the limbs and heart.

Maternal alcohol consumption should be documented in addition to the presence of the above three criteria to confirm a diagnosis. If some, but not all, of the above criteria are met along with documentation of prenatal alcohol exposure, an individual may be thought to have Fetal Alcohol Effects (FAE). FAE is not a less severe forms of FAS, rather it is less recognizable and individuals affected by it are less likely to be identified or to receive intervention.

Effects of Fetal Alcohol Syndrome vary tremendously between individuals. Streissguth, Barr, Kogan, and Bookstein (1996) report that IQ's range from 29-120 for individuals with FAS, and 42-142 for individuals with FAE. Streissguth, Clarren, and Jones' 1985 study (as cited in Streissguth 1994) reported the following adaptive living deficits seen in individuals with FAS or FAE with an average chronological age of 17: an average overall level of adaptive functioning of age 7; performance at an average age of 9 years old in daily living skills based on the Vineland Adaptive Behavior Scale (VABS); performance at an average 6-year-old level in socialization skills; and significant communication deficits. (p.77). In the same article, Streissguth reports that:

> *...even patients with FAS or fetal alcohol effects (FAE) who were not technically retarded were frequently characterized on the VABS by such items as failing to consider consequences of their actions, lacking appropriate initiative, being unresponsive to subtle cues, and lacking reciprocal friendships. (p. 78).*

Two other effects of FAS or FAE that merit discussion are the inconsistent learning patterns and the spotty memory that can be exhibited by many individuals with this diagnosis. Difficulties with learning may be associated with organizational and processing deficits in the areas of information input, output, integration, and memory. (Weiner & Morse, 1994). Although a task may appeared to be mastered one day, the following day, or the following week, that same task may very well need to be re-taught. This is a re-occurring pattern.

All of the above findings indicate that individuals with FAS or FAE may have significant barriers to obtaining and maintaining meaningful employment. It is very important that these individuals receive vocational services by qualified vocational rehabilitation counselors versed in the specific and unique effects of FAS or FAE on learning and performance. Because of the inconsistent learning patterns commonly associated with this disability, performance on standard vocational assessment tools may be inaccurate, or at the very least, only representative of the day the assessment was administered.

Two broadly defined effects of FAS or FAE are due to organic brain differences—sometimes referred to as organic brain damage. These two effects may result in a negative impact on job development, placement, and the successful maintenance of employment: difficulty with interpersonal relationships and social skills; and learning style differences (which include a lack of understanding of cause and effect) which require a need for structure and an organized, slower-paced environment.

It is well documented that individuals diagnosed with FAS or FAE have difficulty with interpersonal relationships stemming from inadequate communication skills, impulsivity and difficulty with social interactions (Aase, 1994). Unfortunately, integration into a new work setting requires all of those skills. Schein (as cited in Millington, Butterworth, Fesko, & McCarthy, 1998) noted that organizational socialization is the "price" of membership the new worker must be willing to pay in order to stay employed. New employees must assimilate to the job site and quickly adapt to co-workers' and employers' expectations. Much of this process relies on an individual's ability to read subtle social cues and adapt based on successful processing of those cues. People with FAS/FAE often fail in the workplace because of the social aspect of work. Social skills training and job coaching are frequently needed (Streissguth, 1997). Streissguth offers this example:

> *Dana, a young man with FAS, had some good "survival skills" but keeping a job wasn't one of them: "I've had lots of jobs, but I have trouble with my memory. I can remember long strings of numbers but still have trouble on the job. I've been trying so hard to get along with people and trying to hold a job, but the people are always the problem. I've had 20 or 30 jobs—what I'd like is to be able to hold a job. I haven't succeeded in holding jobs because I can't find the kind of jobs I like. The kind of jobs I'd like, I'm not trained for. I've tried to train myself, on my own, but it's hard to concentrate—really hard. One time I took a 6-month training program and found a job right away. But usually I get fired pretty*

quickly. People get really annoyed with me. Sometimes I see some problem that needs fixing or something and I make a suggestion and people really get bent out of shape about that. I just can't ever seem to pin down what makes them so pissed off. I feel really frustrated." (p. 198).

Learning style is another obstacle to employment for individuals with FAS. An individual's learning style can be blamed on organic brain differences. Magnetic Resonance Imaging (MRI) has shown significant differences in the brain volume, and structure of the brains of certain individuals with FAS or prenatal exposure to alcohol. (Mattson, Jernigan, & Riley, 1994). These differences in the brain result in differences in learning styles as well as memory deficits. Professionals have spent much effort formulating educational strategies that may be effective with individuals with these types of organic brain differences. Susan Doctor (1994) identified the following eight key intervention strategies:

- Always start with the environment.
- Allow the individual to be a part of the intervention process.
- Don't try harder, try differently.
- Ask yourself: "What is this behavior communicating?" "What would I do differently if I really believed that the individual can't rather than the individual won't?"
- Adapt to individual needs.
- Always provide concrete rather than abstract concepts; lessons taught in context; small steps, taught one at a time; curriculum that is developmentally appropriate; multiple sensory instruction; structure, predictability, routines, and rituals.
- Always build on individual strengths.
- Practice, re-teach; practice, re-teach.

The above strategies should be employed by the vocational rehabilitation counselor to facilitate the job placement and training process. When looking at a job type, a particular work environment, or the level of support that may be required to initially integrate a worker into a job site, these strategies prove invaluable.

Individuals with FAS or FAE learn best with multi-modality instruction. The same concept taught in several different ways (i.e., reading about a task, hearing about a task, and being shown a task) will have a better chance of being integrated into that individual's repertoire of skills. In fact, mentoring or apprenticing is a successful way to teach an individual with FAS or FAE a new job or job skill. Streissguth (1997) relates an example:

Riley had a special skill in his "back pocket," having learned printing in junior high school. When he graduated from high school, he started out working in fast-food chains, like the rest of his friends. He had failed repeatedly in these jobs and become discouraged when a friend remembered that Riley had printing skills and told him about an apprenticeship opportunity. The kindly owner of a small printing company let him serve an apprenticeship for several years, then hired him to work in the print shop. The predictable nature of the work, the patience and kindness of the master printer, and the relaxed pace of the shop all combined in a successful employment experience for Riley for many years. (pp. 194-195)

The above example shows how a structured work environment with a slower, relaxed pace can facilitate the success of an individual with FAS or FAE. The apprenticeship program served as a comprehensive "job coaching" plan where Riley learned at his own pace. He was hired on two years later, presumably after mastering the requirements of the job.

References

Aase, J. M. (1994). Clinical recognition of FAS: Difficulties of detection and diagnosis. Alcohol Health and Research World, 18 (1), 5-9.

Doctor, S. (1994). Intervention concepts. Fetal alcohol syndrome/fetal alcohol effect/fetal drug effect: Educational implications. Paper presented at the Family Empowerment Network National Conference, Madison, WI.

Millington, M. J., Butterworth, J., Fesko, S. L., & McCarthy, H. (1998). Placement constructs and practices. In Parker, R.M., & Szymanski, E.M. (Eds.). Rehabilitation counseling: Basics and beyond. (pp. 379-409). Austin, TX: Pro-Ed.

National Institute on Alcohol Abuse and Alcoholism (NIAAA). (1987). *Sixth special report to the U.S. Congress on alcohol and health.* Washington, DC: U.S. Department of Health and Human Services.

Streissguth, A. P. (1994). A Long-term perspective of FAS. Alcohol Health and Research World, 18 (1), 74-81.

Streissguth, A. P. (1997). Fetal alcohol syndrome: A guide for families. Baltimore, MD: Paul H. Brookes Publishing.

Streissguth, A. P., Barr, H. M., Kogan, J., Bookstein, F. L. (1996). Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) Seattle, WA: University of Washington School of Medicine, Fetal Alcohol and Drug Unit.

Weiner, L., & Morse, B. A. (1994). Intervention and the child with FAS. Alcohol Health and Research World, 18 (1), 67-72.

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Appendix D:

ABBREVIATIONS USED IN THIS MANUAL

ABBREVIATIONS USED IN THIS MANUAL

ADD	Attention Deficit Disorder
ARND	Alcohol-Related Neurodevelopmental Disorder
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
FABS	Fetal Alcohol Behaviors Scale
FAE	Fetal Alcohol Effects
FARC	Fetal Alcohol Related Conditions
FAS	Fetal Alcohol Syndrome
IEP	Individualized Education Plan
IPE	Individualized Plan for Employment
ISP	Individualized Service Plan
IWRP	Individualized Written Rehabilitation Plan
PCP	Person Centered Planning
PWE	Problems with Employment
SIB-R	Scales of Independent Behavior – Revised
VABS	Vineland Adaptive Behavior Scales
VR	Vocational Rehabilitation